

# The Person's Experience of Chronic Condition Self-Management

## A Collection of Case Studies



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Flinders Human Behaviour  
and Health Research Unit

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# THE PERSON'S EXPERIENCE OF CHRONIC CONDITION SELF-MANAGEMENT: A COLLECTION OF CASE STUDIES

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## Acknowledgements

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# Foreword

by Associate Professor Malcolm Battersby, *Director  
Flinders Human Behaviour and Health Research Unit*

I commend a reading of these case studies of people with chronic conditions who have generously provided insights into the complexities, challenges and solutions to these challenges that they have experienced over the course of their lives. These case studies provide lessons at many levels for students, health professionals, educators, people with chronic conditions, their carers, managers and health administrators. These case studies are written by experienced health professionals and community workers who as students of the self-management course, took the time to record the life stories of people from a variety of backgrounds including Aboriginal, the elderly, mentally ill, adolescents, carers, and people from rural, remote and urban environments. The students have taken a self-management framework to look at a person beyond their diagnosis taking into account their upbringing and life experience to understand the person and how and why they manage their conditions the way they do. Each person who reads these histories will gain a deep understanding and knowledge of the incredible burdens that people with chronic conditions face, the emotional consequences for the person and their families, how the relationship with health professionals can be beneficial or harmful, and how the system works for or against the person. It may inspire us to continue to improve the training and education of the workforce and the system we work in and the true collaboration which is required to bring about the best health and wellbeing outcomes for the person and their family.

I would like to acknowledge the students and the support that Sharon Lawn has given to the students in their work to bring these case studies to a wider audience.

# Foreword

by Helen Hopkins, *Executive Director, Consumers Health Forum of Australia*

At the Consumers Health Forum of Australia we seek to provide a national voice for health consumers; to translate the stories we hear from so many of the people in our member networks into ways that help to influence national health policy. This book reflects the kinds of stories we hear daily about the challenges facing people with chronic conditions. Furthermore, it points to opportunities to improve the health system so these consumers can be supported to get the care they need, when they need it.

One of the most significant developments in health care in recent years has been the recognition that consumers want to be involved in decisions about and management of their health care. This is particularly important for people with multiple chronic conditions. Flinders University has developed training programs for health professionals to better support chronic conditions self-management and this book focuses on how some are putting their coursework into practice.

In writing these stories, the health professionals have shown how important it is to listen to the consumer and observe their situation. They heard the consumer's stories, experiences, frustrations and challenges – and their successes – and saw the daily struggle to cope, not just with the chronic conditions, but the often difficult financial, social, family and environmental situation; for example, the lady whose wheelchair could not get in the bathroom, forcing her to use a commode and portable shower. Knowing this, the health professionals were in a better position to support the consumers to self-manage their chronic conditions; to work with the consumer and other health and community workers to find strategies that work for their personal situation.

Another important consumer issue emerging from these stories is the need for health professionals to work together, and with the consumer, to get the best health outcome. The Consumers Health Forum of Australia values team-based care; for example, the team for a person with rheumatoid arthritis may include their GP, the practice nurse, specialist, physiotherapist, dietitian, community care nurse and pharmacist. Support groups, such as those offered by Arthritis Australia, can be an important part of the team as they help the person share ideas with others with similar health challenges about better managing their daily life.

Team members must be willing to share the consumer's care management plan, adding value as necessary and sharing their thoughts with the other team members.

The consumer – and their family and carers – must be at the centre of the team. They must feel comfortable that they are heard and that they can be in control of their own management; however, when that is not possible, that there are people who know and understand them and their condition and who can step in and make sure best quality care is maintained.

These stories will move you. They are stories of people who live in pain, who need to visit health care professionals often and who regularly spend time in hospital. Most cannot work, and must stretch their pension to look after other family members. Many are isolated, unable to physically travel or walk easily, or are prevented from doing so by anxieties.

But many of these stories will also uplift you. They are stories of resilience and perseverance, of good humour and hope, of success in adversity and in taking on new challenges, and of the power of teamwork to make a difference.

I hope this book reinforces to readers that the consumer must be the centre of any care plan. Each person has their own unique situation, which will influence how they manage their chronic conditions, and which should influence how health professionals support the person to optimise their situation, be it through medical intervention or helping the person get the social support to make their life easier; for example, a house with a wider bathroom door.

Many members of the Consumers Health Forum of Australia are illness-based groups that are in an excellent position to support people with chronic conditions, often by putting them in touch with others who are managing their health as part of their lives. We encourage health professionals to ensure that relevant consumer groups are part of their support for people to self-manage their chronic conditions.

# Introducing this Collection

Dr Sharon Lawn, *Course Coordinator, Postgraduate Programs in Chronic Management and Self-Management, Flinders University Human Behaviour and Health Research Unit.*

This collection of case studies was written by postgraduate students within the Graduate Programs in Chronic Condition Management and Self-Management at Flinders University in South Australia between 2005 and 2008. It arose in response to the impact of the uniquely moving circumstances, struggles and triumphs that are captured within each of these stories for me as the course coordinator of this program. Upon reading these stories, I hope that the reader will be as proud of these health professionals (and the people whose experiences are discussed) as I was when I first read their work and that the stories will inform others about the person's experience of chronic illness in ways that advance their knowledge and respect for the person's journey. In particular, these case studies provide the reader with a greater understanding of the beliefs and experiences in a person's life that largely shape and determine how they respond to the challenge of illness management and to health system support.

## **Chronic Condition Self-Management: Are we really listening to the person?**

Much has been written about chronic conditions, their management, and their self-management, particularly since the development of the Chronic Care Model (Wagner, Austin & Von Korff, 1996). A great deal of this literature comes from the perspective of service providers and discusses the many layers of service system organisation and responses. This book is an initial response to this vast literature, borne out of concern that the voices of health service recipients are often lost in this flurry of activity and publication around chronic condition self-management. The assumption underlying much of this international work is that the person's needs and experiences can be clearly defined, that a series of ordered steps, procedures, and systems of organisation will all assist them to become better self-managers, the worker a better self-management supporter, and systems more responsive to the growing burden of chronic illnesses on the health system. We seem to have taken a large step without stopping to listen to and helping the person to articulate the human experience of living with a chronic condition. We make assumptions about and for the person, yet we continue to say that we are working in a person-centred way.

From The Picker Institute, Coulter (2007, Coulter & Ellins, 2006) has provided a useful list of arguments for enhancing person-centred health care. These include:

- Understanding the causes of disease and the factors that influence health
- Self-diagnosing and treating minor self-limiting conditions
- Selecting the most appropriate form of treatment for acute conditions in partnership with health professionals
- Monitoring symptoms and treatment effects
- Being aware of safety issues and reporting them
- Learning to manage the symptoms of chronic disease
- Adopting health behaviours to prevent occurrence or recurrence of disease
- Critiquing and feeding back on the quality and appropriateness of healthcare services

Coulter further states that "recognising these roles and seeking to strengthen them is fundamental to securing a more patient-centred approach to healthcare delivery" (Coulter, 2007, p.1).

However, people's experience of managing their health and making choices about their health is vast, as these case studies will show. Many often struggle to problem solve and negotiate the health system in spite of good self management skills. Some people act passively as recipients of expert advice and intervention, asking few questions, with the consequence of either receiving good service because of their passivity as 'nice' cooperative clients, or receiving little service other than ad hoc responses to issues as they arise, and sometimes too late. The irony of a reactive system is that services only seem to occur in a timely manner during a crisis. This often involves an admission to hospital that may well have been avoided or delayed at the early intervention or prevention end where real benefits could have been made. Some people receive services in good faith and increase their knowledge of how to navigate these systems through experience and trial and error. Others use what 'skills' they have to get their needs met and are sometimes labelled as manipulative or worse because of their assertiveness. System negotiation often requires knowledge, money, experience, personal strength and assertiveness.

This has implications for social determinants of health and how the system responds to and labels users of service. As health professionals, we make assumptions about how people will respond to becoming and being clients of services.

## Introducing this Collection

An interesting exercise it to be on the receiving end of a system where you may be judged, not listened to, or your views dismissed as non-professional and therefore non-expert. People are more than a string of symptoms to be managed with medications and behavioural adjustments. They have complex life histories that impact on their health behaviours in spite of knowing what is 'good for them'. And despite the person's best efforts, they cannot actively participate in life in isolation. Continuous resilience and vigilance is often required to live with a chronic condition and likewise to care for someone with a chronic condition. Corbin and Strauss (1988) define this as accommodation, that is, "the day-to day struggle people with chronic illness and their carers and families make to keep some sense of balance and give meaning to their respective lives as they attempt to manage illness" ( p.6).

There are many costs to living with a chronic condition. Corbin and Strauss (1988) referred to this as, 'the costs accrued by the continuous accommodations that [people] are forced to make in response to the inevitable demands placed upon them by the illnesses and their management (pp.5-6). Register (1987) describes it like this: "Whilst the constant vigilance that a chronic illness requires may be reminiscent of war, how many of us can tolerate being at war with our own bodies over a lifetime – even a somewhat shortened one? Above all, you must choose whether to fight the illness to the death or accept it as your normal state of being. It is a choice that is made over and over again; with each change in your physical condition" (pp. xvi-xvii).

Within the service provider driven interpretation of health, denial, non-compliance and lack of insight are deemed as problems to be assertively addressed with education, treatment and behaviour change therapy. Yet, from a consumer perspective, it may sometimes be a wish to escape the rigors of chronic illness management and to escape being defined as the condition, that is, an act of trying to take back some control within a process that may be perceived to be out of control or a system that is controlling.

The challenge is often to maintain a sense of personal self beyond the illness and to be perceived as so by services and health professionals. A Cochrane review of several randomized controlled trials has shown that compliance to drug treatments for long term chronic conditions on average is 54%, and 50% for lifestyle and behaviour change.

So, what we expect and what is 'normal' behaviour are two very different things (Connors, 2005). We often expect compliance of our clients but disregard our own non-compliance. Health systems in the developed world are dominated by the view that wellbeing is achieved primarily through the modification of lifestyle. Within this 'healthism' realm, self-regulation is viewed as the path to good health and those who choose not to self-regulate or who demonstrate some deviation from this are perceived as somehow lacking or lazy, morally responsible for their situation and blamed, shamed and stigmatised for their circumstances "Under this paradigm, all behaviours, attitudes and emotions that are deemed to put individuals at risk of disease are medicalized and people become morally obliged to correct unhealthy habits" (Paterson and Hopgood, in press). As health care workers, we may often judge people for the choices they make about their health without fully understanding why they make those choices and without fully empathising with their lived experience of having a chronic condition. We do not often acknowledge these aspects in our care plans. It is easy for us to be one step removed. In doing so, we only gain a concrete view of the person and their needs. We miss important information about their needs and coping capacities. We miss who they are as a person and therefore are in danger of overlooking the very things that are often the most important barriers and enablers to them living to their maximum potential despite the presence of chronic illness. Resilience in the face of adversity can be amazing (Deveson, 2003) and the health system can learn a great deal from it. Our standard assessments of the person's self-management capacity arguably could be more consumer-focused by considering resilience factors more, rather than only focusing on knowledge, medication compliance, symptom management and monitoring and other deficits. These approaches imply that the person has deficits that require correction through education and behaviour change. They are only part of the process.

Experience tells us that it is the social, physical, emotional and spiritual impacts that often drive how the person interprets their situation and how they respond. It is not surprising that these impacts have been shown to consistently rate as the most significant concerns for the person in assessment of self-management capacity. It is also not surprising that self-management care plans often identify problems and goals that have little to do with symptom management and medication compliance and everything to do with psychosocial problems, relationships

or other more holistic issues of importance to the person (Battersby, et al., 2007; Regan-Smith Hirschmann, Iobst & Battersby, 2006). An interesting exercise, as health professionals, is to give ourselves permission to reflect from our own personal experience and to speak of and to clients in this way. The health professionals who provided the case studies for this book were given permission to take off their 'professional' hats and to step inside and listen to the person's experience of chronic illness and its management. Students undertaking this postgraduate program were using the Flinders Model as part of their course and many consumers described had participated in the Flinders care planning process with them.

We often associate chronic condition with loss, grief and adjustment to a new identity that is somehow less or that denotes some sense of disadvantage for the person (Corbin & Strauss, 1988). However, for some people the development of chronic illness may be a cathartic experience that results in beneficial changes that add value to their lives and their world view. They may strive to achieve goals that they previously postponed, to gain more meaning from their lives, and become more determined to contribute to the lives of others. Chronic illness may give them a new perspective that, rather than diminishing their lives, actually enriches it (Deveson, 2003). This can also be so for their loved ones.

Another issue with much of the current literature about the Chronic Care Model is that the bulk of solutions for better self-management and self-management support continue to be interpreted as residing with health service systems. Wagner's model talks about availability and access to community resources as an overarching domain; however, there is a sense that many authors merely pay lip service to this aspect without fully integrating it into their discussions; the diversity of those community resources and issues such as the determinants of access and availability are therefore lost in the translation. The WHO Innovative Care for Chronic Conditions (ICCC) framework, developed by Epping-Jordan et al (2004) as an adaptation of the Chronic Care Model, describes a dynamic partnership between the patient and family, healthcare teams and community partners.

People with chronic conditions (whether they are in their own homes, in hostels or in institutions) 'live' within the community. Their complex life histories often involve compounded disadvantage caused by varied and powerful determinants outside of the direct influence of the health care system that may vary for reasons beyond the person's

direct control. We have known this for some time.

Taylor (1979), for example, refers to these as predicaments and argues that, "many of the sources of human distress manifestly come from difficulties which are beyond medical remedy" (p.1010).

Taking appropriate action to manage and cope with the symptoms of a chronic condition assumes that the person has access to the resources to facilitate this. Yet there are many in the community for which this may not be the case. To demonstrate this point, the experience of Indigenous Australians is a useful one. In several indigenous communities in Australia, the health impact of low-socio-economic status, low incomes, poor living conditions, the excessive consumption of alcohol and other harmful substances, and inadequate nutrition combine to create a typical pattern of early deaths from injuries, cancers, cardiovascular diseases, and chronic health conditions such as diabetes (O'Dea, 2005). Understanding the person's real experience of poverty and doing something about it would seem to be needed. Within such communities, an assessment of self-management capacity that looks solely at improving knowledge, symptom management, medication compliance, and physical and social activities, without also understanding and actively addressing social determinants of health is not only naïve; it is doomed to failure.

So where does this leave us? Consumers are striving to have a voice and thankfully, this voice is being driven from the area in which it is arguably most needed; mental health. Out of the greatest compounded adversity, good things often rise. The concept of recovery is currently being used in an attempt to redefine the mental health system, largely led by consumers (Davidson, O'Connor, Tondora, Styron & Kangas, 2006). The general health sector is increasingly taking this concept on board. Recovery oriented service, as defined here, is that which, 'identifies and builds upon each individual's assets, strengths, and areas of health and competence to support the person in managing his or her condition while regaining a meaningful, constructive sense of membership of the broader community' (p.641). This seems to be a positive approach when developing strategies to support people to minimise all these accrued costs from chronic conditions generally. At its core are respect and hope and truly understanding the phenomenon from the person's perspective. It is not a new concept; it is just time to start delivering on it.



# Introducing this Collection

The contributors to this book were given permission to capture and reflect on the private and the personal in the lives of their clients, in their day-to-day experience of living with chronic conditions. Within busy systems, we often don't allow ourselves time to reflect, let alone fully listen to the person's experience. We often don't ask people what they are doing in the first place and what their meaning of health is. We often look for deficits and neglect to see and acknowledge the strengths that people possess. This is unfortunate, with real consequences for the quality of support we provide, its effectiveness and their health outcomes.

By presenting this collection of case studies, I hope to promote understanding and raise the voice of people living with chronic conditions. This book is therefore for consumers, health professionals and teachers. Pseudonyms are used for each consumer described within this book except Kim and her mother who were happy for their real names to be used, and all gave their consent for their stories to be told. Some authors have also requested anonymity to further protect the identity of the people described in their case study. The Flinders Human Research Ethics Committee provided confirmation of the ethics of this undertaking.

## Notes for Health Professionals and others providing support

A selection of the case studies from this collection has been chosen to provide some additional notes for workers and others who are involved in providing self-management support to people with chronic conditions. These may include medical, nursing and allied health professionals and other workers involved in providing support services, plus formal and family carers. The aim is to articulate potential relevant engagement issues from the person's perspective that may help guide worker interactions and assessment. Following from the intent of the case studies, these notes discuss strengths, barriers to and opportunities for the person's engagement and ongoing work with service providers drawn from an understanding of the person's holistic experience of self-management and their circumstances, with implications for how effective CCSM support is provided. The assumption is that we each draw from our past experiences which in part shape who we are, how we define ourselves, how we see ourselves in relation to others, and how we approach and cope with new situations. This varies for each individual and is a dynamic process that is always more complex and layered than the limits of service assessment processes portray.

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## John's story:

# “Blokes don't break down”

by Deborah, *Clinical Nurse Consultant - Heart Failure, South Australia*

JOHN is 87 year old war veteran. He is in receipt of a Department of Veterans Affairs pension and is a Gold cardholder. Eighteen months ago John and his wife moved from the country into an independent living unit in the metropolitan area for the purpose of improving access to specialty treatment for John's chronic conditions. During his last admission seven months ago his wife who was his primary carer, unexpectedly died. John has outlived his only child a son who died 15 years ago of acute myocardial infarction at the age of 45.

For the past five years, John has had up to three hospital admissions per year for acute exacerbations of his chronic conditions. He has a history of coronary artery disease, hypertension, ischaemic heart disease, atrial fibrillation, chronic heart failure, anxiety, and chronic obstructive lung disease on a background of long standing asthma. John has had bilateral hip replacements one of which was successful; the other has resulted in a chronic infected state surrounding the prosthesis requiring the use of permanent antibiotic therapy. John has exertional hypoxaemia requiring the use of home oxygen therapy, and significant pharmacotherapy. John's oxygen prescription is for 2Lpm with exertion. John only uses his oxygen at rest and has been observed to use it primarily with anxiety.

John has been an ex-smoker for some 35 years with a 35 year history of smoking. John's current body mass index (BMI) is 19, though in the past his BMI was as high as 30. John regularly attends his local RSL club in which he freely admits to drinking alcohol at what is recognised to be harmful amounts. He is actively involved with his church and attends social activities in the communal dining room at his village. He has lunch and dinner in the communal dining room and prepares his own breakfast. John has had periods within his life where he was physically active though he admits that that was some time ago. His current exercise tolerance is 50m on the flat before severe dyspnoea necessitates a rest. John still holds a current drivers license and drives locally.

It appears John has had asthmatic like symptoms since early childhood though the diagnosis was not made until he was in his 40s. Both of John's parents smoked and as was common during that time they smoked inside. John recalls he often had a cough and often had bronchitis when he was growing up. He enlisted at 17 and went to war where he learnt the art of smoking. Cigarettes were usually in the ration pack and were given as reward. A sense of belonging and sense of camaraderie developed, many a story told over a cigarette. John was captured by the Japanese and became a prisoner of war. During this time his weight plummeted. He took up a position as a cook in the kitchen cooking for the Japanese which he credits to his survival. John's diet during his early years consisted of food laden in high saturated fat and salt. Post-war access to quality food was limited; “People just learnt to work with what they had. You made do”.

For most of his life John has been unaware or ambivalent of the chronic conditions he has had. The exception to this was the osteoarthritis in the hips which caused him great pain and limited his walking. In the absence of symptoms he could see no harm and in the presence of chronicity he could see no symptoms. John could not see the increasing shortness of breath on exertion; this was easily dismissed as getting older and not being as fit. John could not see the coronary heart disease, the chronic hypertension or the remodelling taking place within the heart, or the weight around the midriff. These chronic conditions were not new to John. They were meaningless to him; he still felt the same. It was 20 years ago when John was diagnosed with ischaemic heart disease during his first hospital admission for chest pain. It was then that the previous diagnosis took shape and meaning. Now John had meaningful symptoms. John adopted a new lifestyle on discharge. He increased his level of activity and made some changes to his diet which resulted in weight lose and a reduction in his symptoms. John continues to use salt since he finds food unpalatable without it. John's cardiac condition has progressed due to age related changes, poorly controlled hypertension and the development of an arrhythmia. John was placed on an anti-arrhythmic drug. He believed the drug was damaging his lungs so stopped taking it; his doctor is unaware.

## John's story

Over the years John was prescribed a variety of preventative respiratory medications, none of which he believed was effective so adherence was an issue. John continued to reach for his Ventolin since that was the one medication that had the greatest efficacy. However this was also the drug which exacerbated his arrhythmia. John was able to give up smoking 'cold turkey' when it was explained that his respiratory symptoms were related to his smoking.

John's breathing problems were upgraded from asthma to chronic obstructive airways disease after recurrent episodes of bronchitis and eventually pneumonia severe enough to warrant hospitalisation with an episode in the Intensive Care Unit (ICU). It was during this admission that his wife died. John has Type 1 respiratory failure and was discharged on home oxygen therapy.

John's experience with osteoarthritis has been mixed. One hip causes him no problem whilst the infected site causes him significant pain and limits his mobility. The mobility limitations have impacted on his cardiac and respiratory health, both of which advocate aerobic and strength building exercises. John has so many medications to take, some of which he has not been taking since he sees no benefit. A number of these medications are important management strategies which would assist John with symptom control. A barrier to medication adherence is the financial burden of disease. A number of the medications John is required to take are not included under the pharmaceutical benefits scheme yet are well recognised as evidence best medicine such as Glucosamine. The costs of some of these medications are beyond the means of those most likely to need them; the aged.

John has frequently demonstrated the ability to change harmful behaviour or adhere to recommendations in the presence of a reasonable explanation. He has successfully given up smoking without assistance and until the pain in his hip became problematic initiated and maintained an exercise routine. John has consistently in the past made decisions based on perceived benefit and exercised informed non-adherence. In recent times John has not felt much like exercising, his weight has plummeted, and he has become emotionally labile shifting from anger to tears readily throughout the consultation. John has some social interaction on a daily basis.

John believes he is one of the lucky pensioners, his Gold Card providing him with access to services and treatment that old age pensioners either do not get or have lengthy waiting times. He also has a "few more pennies in the back pocket". John has had an occupational therapist perform a home assessment and a physiotherapist to assess his mobility. Necessary equipment has been provided at no cost to John. John has had a social worker visit him in the early days and is in possession of a good community aged care package. The package also incorporates provision for social support. John's GP visits him monthly and he sees a cardiologist, a respiratory physician, and an orthopaedic surgeon regularly with transport provided, and a respiratory educator who visits him in the home.

John is typical of a group of patients I visit in the community to provide in-house education and support for home oxygen therapy. His chronic condition management is complex with one condition often affecting another. John has, prior to his wife's death, been able to manage his conditions when provided with adequate information. John's ability to effectively manage his conditions in the presence of poor coping mechanisms, since his wife's death, has become problematic. Consultations or service provision which are there to service one problem are consumed by the patient's grief and the inherent loneliness which ensues. John's ability to remember management strategies is impaired by his grief. John frequently rings the office wanting to talk to the respiratory nurse. The conversations are long and though they start off with a question related to his respiratory status the focus soon switches to his wife and the life they had together.

When a pattern of behaviour develops in which the nurse becomes John's support person it becomes evident that John would benefit from some counselling either through his doctor or through his church. Although John has a doctor who regularly sees him he does not feel comfortable talking to him about his emotional state; "Blokes don't break down". John feels the doctor always seems to be in a hurry, plus he has not known him for very long and does not know how to broach the subject. John has few real friends in the city and most of his friends are dead now also. Though he attends his church and regularly attends bible study, there is not a sense of belonging. He attends his local RSL club weekly but puts on a brave face.

John is an interesting case. When one glosses over what is available to him and what is utilised, he appears to be better off than most. Loneliness and grief are having the biggest impact on John's life and interfere with his ability to effectively manage his conditions. John has been provided with social support, belongs to a church group, attends his RSL club and attends all village social activities. Though John is socially active he is missing social integration. He also believes he is perceived with his oxygen bottle as diseased and disabled effectively further socially isolating him. He chooses to not use his oxygen outside the home because of his perception of how people see him. He believes he looks weak and pathetic and does not tell the other veterans he is oxygen dependent. He has moved from a small intimate country community with a wife of nearly 60 years and ended up a widower with no one to discuss his grief with. If he had stayed in the country he would have had people he could have talked with about his experiences of losing his wife. The social structure of a small community has the ability to negate the need for provision of social support which is often provided at a superficial level. However he would not have had the access to the specialist care which he requires. At his age and with his level of disease burden it is difficult to fully integrate into a new social group.

With the consent of the patient the nurse takes on the role of advocate and contacts the doctor, sharing concerns highlighted from the in-home consultations. It is hoped the catalyst for discussion has been provided and the barriers removed between the patient and his care giver, enabling the patient. His local church was contacted to address how better they could service their patron. It was also suggested the taking in of a boarder perhaps a widow/widower may help to alleviate some of the loneliness and may service the need of another lonely elderly person. The provision of service is perhaps not as important as the social structure one finds oneself in. Having increased benefits enabling acquisition of services may not translate into effective use of services for the patient or the provider if the disease context fails to address or identify the social connotations past and present. Having increased benefits does affect choice; however the disease burden of the elderly person effects the distribution of these benefits.

## Joan's story:

# Life wasn't meant to be easy!

by Rhonda, *Physiotherapist, Community Health Service, Victoria*

JOAN is a 64 year old lady who has chronic asthma, cataracts on both eyes, one with a growth between two lenses which causes blurred vision and an ear condition which requires two weekly manual removal of the wax by a specialist. The accumulative effects of medication, namely cortisone, have caused osteoporosis and an ongoing roller coaster of weight control and high blood pressure. She has recently been diagnosed with a deep vein thrombosis in her left leg. Joan has had asthma all her life, but states it became chronic ten years ago. There is a history of operations on both eyes for cataracts and she requires another operation for the growth between the lenses. Joan also wears a hearing aid in her other ear.

Joan was widowed in 2000, her husband passed away after a five-year history of bowel cancer. She has three sons, all in their mid to late 30s. The eldest has epilepsy, cerebral palsy, hydrocephalus, asthma, is legally blind and deaf and is currently being treated for depression. He lives at home with his mother, works at a workshop for the disabled plus at the local pharmacy. The middle son is epileptic, asthmatic, intellectually disabled and legally blind. He moved to a community residential unit a few years ago. The youngest son has full-time employment, lives at home and has recently been diagnosed as having an intellectual disability, this being identified after trouble with the police around an issue of violence. Joan owns her own home and receives a carer's pension for the care of her middle son. Both her husband's and her own family live interstate. Despite this, Joan does have a strong network of friends developed from childhood.

Joan approaches life with a philosophical attitude. Her health is "life"; it requires a balance between minimizing aggravating factors without allowing the illnesses ("it") from stopping her from daily chores, socialising and supporting her family. An excellent example of this is how she responds to cold weather and northerly winds, which trigger her asthma. She keeps an eye on the weather report. On a good day she gets out, walks everywhere and does as much as possible outside. If there is a north or cold wind she finds one of the many jobs she has to do inside the house. To maintain physical well being she has a gym membership and attends as often as possible, returning as soon as acute episodes subside.

There can be difficulties with membership when she regularly needs to have a break, to address this she has negotiated a special deal with the leisure centre. If there is a planned social event, she "just adapts", organising a change of plans with her friends. "Life is give and take, often we need to change plans for them too, they don't mind and neither do I. We all need to be realistic".

The health care workers Joan is involved with include a GP, asthma specialist, osteoporosis specialist, ear specialist, eye specialist and Pharmacist. Over the years she has developed a collaborative relationship with the individual practitioners, working from the premise that, "you have to ask, otherwise they won't tell you". "I make sure I tell them what I am doing and the final decision is mine". Joan has regular episodes of bronchitis, is aware of the tell tale symptoms and has pre-organised scripts to ensure she treats infections and asthma aggressively and quickly, even down to knowing what dosage is required for the presenting severity. Although between her sons and herself she visits health professionals regularly, with an acute episode she only makes telephone contact to inform the GP or specialist of what is happening and discusses any problems if they arise. As she has been taking medication since childhood, she has a unique understanding of both benefits and side effects, for example, cortisone can trigger another bout of asthma if the dosage is not decreased slowly.

Although money is an issue, Joan and her husband were good money managers and this now holds her in good stead. To manage she has a budget, plans for the future, makes contact with social workers to solve money issues, negotiates payment plans and keeps abreast of her entitlements. Realistically, a car is unaffordable, but Joan believes it necessary for emergencies. "I make sure I keep the maintenance up to minimize unexpected costs and go without other things to keep it". It is in this arena that her quality of life is eroding, now unable to afford private health insurance, Joan has had to stop going to the movies and is in an untenable real estate situation. Her house is requiring maintenance but down sizing whilst staying in the same community is not financially viable.

Joan scores well on the self-management criteria. She has knowledge of her condition and treatment, she actively shares in decision making, she monitors and manages

signs and symptoms, manages the impact, adopts a healthy life style and focuses on prevention and early intervention and confidently uses support services. Joan is unique in that any care plan that may be described is of her doing and she has personally resourced and developed relationships with practitioners who consequently respect her self-management skills and her personal situation. Joan portrays empowerment and confidence. She is an assertive equal partner and openly involves support people to assist in navigating systems (Lawn, Battersby & Pols, 2005). Rogers et al (2005) presents the whole system approach, suggesting at the patient level it is important to provide relevant and accessible information; at the professional level it is important for the professional to respond in a flexible, patient centred manner; and at a systems level to improve access to services by providing flexible access arrangements. Joan and her health care providers optimise this approach. This must be a pleasure for Joan and all health professionals who share in her care.

As a society we applaud Joan for taking personal responsibility for her life. One must look at the historical context of her life to start to understand how she has managed to be so successful. There is no doubt that Joan, her husband, friends and children would have been dealing with social justice issues at every level and every stage of their life. This requires a clear understanding of an expected quality of life and a belief that there is a way around all obstacles put in the way. Also, 'acceptance' of illness as 'normal' (Register, 1999) would have occurred a long time ago. Ironically, it is her and her children's health that is a major part in the creation of the social inequity she is currently facing. The accruing financial cost of her health is the single biggest issue that is slowly eroding her quality of life. Even so, Joan is a picture of 'RESILIENCE', that is "the human capacity to face, overcome, and even be strengthened by experiences of adversity" (Deveson, 2003, p.37-38).

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### Notes for CCMS support people

#### STRENGTHS

Her capacity to endure.  
Her positive attitude to life and her circumstances.  
Despite the many demands on Joan, she has maintained a strong network of friends.  
We could expect that Joan is a very good organiser of others and someone who follows through on tasks, once set. Her good financial management is an example of this.  
Joan's network of health care providers respect her and are flexible in their approach.  
Joan's knowledge of her health conditions and her self-management skills.

#### BARRIERS

Her sense of carer obligation to her children who have multiple psychosocial needs.  
The sheer volume of needs of her children makes her life a very busy one with potentially little time for her own needs.  
We could expect Joan to be a strong person who may not accept help readily, unless she feels she needs it.  
Joan seems to have drawn the short straw in having multiple health conditions from a young age, despite her good self-management skills.

#### OPPORTUNITIES

Joan has a potentially long history of dealing collaboratively with service agencies through her experience of parenting children with disabilities and navigating quite complicated situations and service systems.  
Joan is comfortable being assertive and open with service providers.  
Joan's dedication to supporting her children can be harnessed, using the rationale of 'looking after herself in order to ensure her ability to continue in this role'.  
Despite their disabilities, Joan's children who currently live with her both work, so there is a sense that they are maximising their potential. Joan's attitude to life may well have influenced this.

#### IMPLICATIONS FOR CCSM SUPPORT

Joan has likely put her own health and other needs last. Her dedication to her carer role may in part be due to a lack of adequate services for her children in the past. Respite and other supports should clearly be explored.  
Joan has been a very independent woman who will not give this up lightly. Workers will need to be sensitive to this as her health and capacity to drive, for example, diminishes.  
Health professionals may be inclined to step back, not ask or not check out different options or treatments because they have come to expect and assume that Joan has control of what she is doing and that she knows best. Some needs may be overlooked as a result.

# An active yet uneasy partnership

by Anna, *Senior Physiotherapist/Acute Inpatient Service*

RUTH is a 61 year old woman, living alone independently in her own home in an outer suburb of an Australian capital city. Her interests include walking holidays, current affairs and social justice issues, listening to ABC Radio National and reading. Her two adult children live nearby with their partners and children. She has three grandsons under the age of four. On four days per week she spends time caring for one or more of her grandsons.

Ruth has a number of chronic conditions:

- Psoriasis since age 14, which has been 'severe' for about the last 10 years, with greater than 20% of her body surface area covered. Previous treatment had been with tar topical therapies, topical steroids, and one course of oral steroids four years ago (ceased when diabetes was diagnosed). She uses no current medical treatment for her psoriasis.
- Non-Insulin Dependent Diabetes Myelitis (NIDDM), diagnosed four years ago during treatment for psoriasis with steroids. Her Blood Glucose Level (BGL) was 22 on diagnosis and her HbA1c has been 6.4 and 6.1 on the last two of her three monthly tests. She currently controls her diabetes with a 'diabetic' diet and exercise. She measures her blood glucose levels three times a day on every second to third day. Ruth also does at least one hour of moderate intensity exercise, 5 to 6 days a week (some days doing greater than 1 hour).
- Worsening vision due to cataracts. She plans to have surgery within the next 6 months.
- Intermittent recurrent shoulder pain (bursitis), and back and knee pain (osteoarthritis), managed with physiotherapy and exercise and occasionally anti-inflammatories.
- Raised cholesterol diagnosed 11 months ago (5.2), managed with a Statin and diet changes (now 3.1).
- Slightly overweight with a BMI of 26.
- Her blood pressure is within the normal range.

Ruth doesn't drive, choosing public transport and walking as her most common forms of transport. Recent public transport changes in her area have decreased her public transport options.

Ruth's current interaction with health care services includes:

- 3 monthly blood tests and review by GP and Practise Nurse for diabetes and cholesterol management.
- There has been a recent change to point of care blood tests at her GP surgery (rather than blood tests at a pathology collection centre some days prior to GP visit). She feels this has significantly reduced the time cost of her reviews.
- Recently commenced on a Chronic Disease Management GP Management Plan and a Team Care Arrangement. She is now able to access Medicare funded podiatry 4 times per year and a dietitian review. Ruth had requested this from her GP, being aware of the recent changes to Medicare funding for chronic illness from listening to ABC radio. Prior to this she had been finding the combination of medical, medication and private allied health costs increasingly difficult to manage.
- She also has an ophthalmology review annually.

When initially diagnosed with diabetes Ruth attended a seminar at her local hospital diabetes education centre. She is a member of Diabetes Australia and finds reading their publications very useful. Since Ruth was diagnosed with diabetes she has displayed an ability to effectively use healthy behaviours. She has consistently used exercise, appropriate diet, and medication as prescribed to control her diabetes and cholesterol, and has attended regular medical reviews. She has a good understanding of how diet and exercise affect her diabetes and cholesterol. She regularly measures and records her BGLs, and adapts her behaviour effectively as needed (though with more difficulty for weight control recently). She feels confident in her ability to control her BGLs with her current level of disease. Her main difficulty has been during two episodes of exacerbation of knee pain, which limited her ability to exercise at her usual intensity. She is aware she could do exercise in water when she has pain, but feels uncomfortable exercising at her local pool due to her perception of other people's discomfort at seeing her psoriasis. During this time she gained a small amount of weight, and is aware of how this has affected her diabetes control. She is actively working on losing weight.

Balancing the needs of multiple comorbidities has been noted as a common barrier to effective self care (Bayliss et al 2003). Her goal is to continue with minimal medication, and use 'lifestyle' methods to control the diabetes and cholesterol.

Interestingly, in contrast with many people (Nagelkerk et al 2006) Ruth reports it was relatively easy to succeed in being consistent in the 'lifestyle' of diabetes control, but the greatest burden to her has been coping with the need to have frequent ongoing contact with health workers. Prior to being diagnosed with diabetes, she had irregular contact with health workers, despite her other longstanding conditions. She felt she did not have open communication with the GP she was seeing at that time, though she never discussed this with him (she feels she avoids any potential confrontation with those she perceives as authority figures). She then lost confidence in him when she discovered he had not explained to her the potential side effects of the steroids prescribed for her severe psoriasis. She changed to a GP with a more collaborative style recommended by friends and family. She now feels she has a very good relationship with her GP. Ruth feels her GP has respect for her knowledge, opinions and self-management skills, and has explained things to her comprehensively. The monitoring and treatment plan for diabetes recommended by her GP corresponds with the Australian Guidelines, and Ruth is aware of the appropriateness of treatment through her reading (eg Diabetes Australia literature she receives as a member). Despite this, she reports she feels "trapped" and 'chained to the doctor's surgery' due to her three monthly blood tests and reviews. She also reports anticipation of upcoming appointments causing her a lot of stress, particularly when she needs to see a new health worker and is aware she finds excuses not to book appointments in order to delay the stress. She reports that while she understands the logic of good diabetes control to minimise future complications and optimise her independence and quality of life, this is not the reason she "complies". She feels she has a very strong underlying fear of "getting into trouble" with her doctor. She feels this is related to her fear of her father as a child.

Ruth feels that when she was a child her father had a very authoritarian approach with her. She felt he treated her quite differently to her sister and brothers, that he was "very controlling". She says she felt she had to do 'everything right' and be very careful around him, as she could easily "do the wrong thing and make him angry", perceiving she was often blamed for things she had no control over. She feels that this has left her with a very strong need to remain in control of her life, and she has difficulty dealing with "authority figures" such as health professionals and others with official roles. In recent years, not long before he died, her father told her that he had never believed that she was his child, as she was born "too soon" after he returned from the army after World War 2. She feels this explains why she 'was treated differently' to her brothers and sisters. Ruth has discussed her thoughts on this with her GP, and while she feels the GP does not appreciate just how much stress it causes her, the GP does assist her by having reception staff book future appointments before she leaves the office.

There are other aspects from earlier in her life which Ruth feels influence her current health status. She feels she has a perception stemming from her childhood that going to a doctor meant that people were going to become sicker and die. Her mother was diagnosed with cancer when Ruth was eight years old and died four years later. She recalls her mother as a previously strong woman, becoming confined to bed after seeing doctors, and later dying. Later in her life, Ruth's husband also became unwell suddenly with severe headache and limb weakness at the age of 46, and died a month later from brain metastases from a previously undiagnosed malignant melanoma. Her own treatment of psoriasis with steroids resulted in the diagnosis of diabetes. All of this further reinforced her discomfort with medication and medical treatment. Ruth also feels she has some difficulty communicating her symptoms effectively with healthcare workers. She possibly uses terms which under-emphasise the severity of her own pain. She recalls dressing her mother's radiotherapy burns as a child, and feels she interprets and describes pain from the perspective of her perception of her mother's severe pain at that time.



While the major focus of healthcare intervention has been on diabetes management, when asked to list her health issues, Ruth listed psoriasis first and on questioning confirmed it has the greatest impact on her. She feels all health workers she has dealt with have underestimated its significance to her and recalls having been told more than once "at least you won't die from it". To date she has not found a treatment which has significantly helped her. She feels it is the only condition she has which she has not been able to manage effectively. She feels most health workers have considered the aesthetics and skin scaliness, but have not been able to appreciate how painful it can be or her difficulties with skin cracking and bleeding. In a survey of more than 1300 people with psoriasis, 21% rated burning pain and 29% skin bleeding as significant concerns. Also, 78% were frustrated that treatment did not make their condition more manageable, and 59% felt that their doctors could be more helpful in assisting them to live with psoriasis (Krueger et al 2001). It has been noted that there is a low level of agreement between doctors and patients about the level of psychological distress for those with psoriasis (Richards et al 2004). Finlay (2001) commented that doctors are not good at estimating the impact skin diseases have on individuals and that severe psoriasis can cause similar life impacts and disability as other major medical diseases such as angina or hypertension. Significant stress has also been reported relating to fear the condition would worsen, misconceptions by others that the condition is contagious, embarrassment, and feeling excluded from public places such as pools, health clubs, hair and beauty salons. etc. A small number (8% of those not employed) felt excluded from working outside the home (Krueger et al 2001).

Ruth left school at age 14, soon after her mother's death, working until she married at age 20. She felt her role as primary caregiver raising her two children was an important one during their childhood years. However she felt stigmatised by "ignorance about psoriasis", and felt excluded from employment due to both this and her limited education and work experience. Since the death of her husband when she was 43, she has been on a fixed income from his superannuation fund. Not yet qualifying for a seniors health care card, she has found she has been increasingly "trading off" priorities to afford her medical costs and, until she recently discussed this with her GP, it appears that her GP considered her able to afford private allied health therapies.

She places a high value on her contribution to the raising of her three grandsons. She does, however, report a conflict between needing to limit the amount she is available to care for grandchildren in order to look after her own health, against feeling she has "waited so long to have grandchildren" and wanting to "enjoy as much time with them as I can". She expresses resentment towards illness limiting her capacity to do this. However she also appears to have a strong feeling of responsibility to assist her children and grandchildren, and appears to often choose to put her health concerns second. Whilst her children live nearby and she feels she has family support and help when needed, she reports a strong need not to be reliant on anyone and needing any help does cause her some stress. For Ruth, her main issue is stress related to managing her conditions, and concern for the future, particularly the potential of worsening health, increasing financial burden, need for increasing interaction with health workers, likely need for increased medication usage, and fear of losing independence and control. Despite appearing to be a good self manager, with good disease control and active in seeking healthcare providers and services to suit her needs, for Ruth there is still some disparity between the focus of care (diabetes/cholesterol) and her main concern (psoriasis), and a lack of depth of understanding by her healthcare providers of the level of stress and anxiety caused by her conditions and their consequences.

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# Complex co-morbidity

by Leanne, *Inpatient Services Social Worker, Victoria*

### Background

NOEL is a 52-year-old man who I met on his 35th admission to hospital. My role as a social worker in an acute medical hospital is varied; I look at psychosocial issues and aspects of a person's health, adjustment to illness, linking into community services and discharge planning as well as grief and loss issues, provision of Centrelink information and assisting with the transition to residential care if required.

Noel's medical history is complex. He has Haemophilia A, cirrhosis, Hepatitis C (presumed origin from a blood product transfusion), encephalopathy, obesity, depression, impotence, postural hypotension, and chronic pain due to osteoarthritis in his knees. He has also had an aortic valve replacement.

Noel had previously been in full-time employment before developing so many complications with his health. However he has not worked for many years. He lives with his wife, Sarah, who completed a university degree two years ago. Sarah has only been able to work in a relieving capacity due to Noel's fluctuating health and care needs. The couple have two sons, Christopher, 20, and James, 17. Christopher moved out of home twelve months ago due to conflict with his father. He works as a delivery driver for a local company and his partner has recently given birth to their first child. Christopher and his partner have a difficult relationship and their child is currently being cared for by Sarah and Noel in their home. There are ongoing issues around long-term custody and care of the child. James is currently completing his VCE at the local secondary college. Noel has just been discharged after his 41st admission to hospital.

### Discussion

Noel has a very good understanding of his complex medical issues and he is very proactive in accessing medical assistance when needed, he keeps in contact with his various medical practitioners, is aware of the various tests and pathology results that pertain to him, and is involved in accessing support through the internet and other available means. Noel would appear to be doing everything that chronic illness self-management programs suggest to maintain optimal health and control over decision-making regarding his illness (Wagner et al, 1996; Rothman & Wagner, 2003).

Whilst Noel has shown a broad depth of knowledge regarding his health conditions and their impact upon his life, his lived experience of illness is compounded by the various systems that he has to deal with. Noel has developed a good relationship with his doctors at the consultant and GP level. However, when he is in hospital it is quite different. Many of the nursing staff have verbalised to me that they feel that Noel and his wife treat the hospital as a respite facility. They do not understand that Noel is able to identify the early signs of the exacerbations of his illness and proactively gets himself to hospital as needed. These actions are perceived by nursing staff, and the junior medical staff, as 'not coping', rather than as exacerbations of his multiple medical concerns. Attitudes such as these undermine any sort of control that Noel might feel in regard to his illness and the management of it (Wilson, 2002; Paterson, 2001).

Another impeding factor in Noel's ability to manage his health is the need to manage more than one condition. This means he sees different specialist physicians for his various illnesses, and when he is in hospital, he may be under the care of one of these specialists. However, the others may not see him at that time. He may be admitted to one of many different wards within the hospital depending upon his presenting condition. This may mean that he encounters different nursing staff, medical staff and allied health, including Social Work, resulting in a very fragmented service that lacks continuity of care for Noel and his family.

## Noel's story

The public health system does not provide the necessary time or incentives for adequately allowing the management of a patient by more than one team per admission. Stille et al (2005) discuss the benefits of 'care coordination' to enhance health care across different settings however this is still an elusive goal, as differing organisations compete for limited health funding to implement or establish such programs. In the Victorian hospital system there are teams of 'Complex Care Coordinators' as well as 'Admission Risk Teams', both of which have as their goals, the reduction in hospital admissions by people with chronic illnesses.

These two teams are funded through the Hospital Admission Risk Program (HARP 2005) but their ability to coordinate teams of care and services across the acute, sub-acute and community sectors is still very limited. The complexity involved by the differing systems and the complex social situation of people such as Noel mean that any decision-making is made even more difficult by the existence of comorbid conditions. As Bayliss et al (2003) note, the existence of comorbid conditions creates barriers to self care strategies as well as correlating with an increase in depression which further impacts on a person's ability to make decisions in regard to their chronic illnesses.

Noel's interaction with various support services has been spasmodic. He has been referred to the Admission Risk Team but did not feel that they were able to offer him anything more than the support he was already obtaining. Noel is in the unfortunate position of being too young to be eligible for the Aged Care system of services. Whilst he is on a disability pension and able to access Home and Community Care (HACC) services, these are limited to in-home respite, home care and Meals on Wheels, none of which are particularly useful to Noel or his family. Noel's social situation is such that the support he requires is more around socialisation opportunities which are limited to Adult Day Centre programs which are utilised by people far older than Noel. The disability sector is still predominantly focused on people with an Intellectual Disability, which again precludes Noel. Initiatives such as the Service Needs Register (Dept Human Services, 2005) are under resourced and unable to cater for someone in Noel's position.

Due to a lack of available alternatives, the local Aged Care Assessment Service has become involved with Noel and approved him for residential care, however he is reluctant to utilise either respite or long term care due to his age and his desire to remain at home as long as possible. Financial reasons also underpin this reluctance, as the couple have an investment property that was initially bought to assist in providing for them both in their retirement. Due to the existence of this property, the financial contribution required by Noel to access residential care is prohibitive, he still sees the property as needing to provide for Sarah in her retirement, and now with the addition of a grandson to care for, there is even more financial stress on the couple.

The geographical location of the family is also impacting on their ability to access services and support. They live in a small regional town where there is little in the way of residential care facilities. Most people know each other so privacy and confidentiality is an issue and the couple don't want to be labelled as 'not coping'. Noel is a very private person and does not wish to be a burden on his wife and family. However, he also does not want his neighbourhood community to be providing the in-home support necessary.

### Conclusion

There are many impediments to people such as Noel and Sarah in accessing adequate health care and being able to maintain their own level of choice and autonomy in such care. A person's social situation greatly influences the degree to which they are able to maintain self-management. As well as this there is the interaction with different health professionals who may not share the same goals or philosophy regarding their care.

The health system in Victoria is not yet at a point where there is sharing of information or knowledge between the various agencies providing care. This makes for a very fragmented service in which individuals and their families are left struggling to achieve self-management.

The nature of chronic illnesses is such that there will always be fluctuations with a person's health irrespective of the level of compliance with medications or health care regimes. The acute hospital setting is not geared to cope with these recurrences of illness, and more needs to be done in training staff to deal with and accommodate people who are able to maintain decision making in respect of their illness, whilst in the acute setting. Staff also need to develop an awareness of the complexities of such illnesses and the impact felt by patients and families so that they are better able to support them during periods of hospitalisation.

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# Trapped

by Marilyn, *Clinical Nurse Consultant, Queensland*

EMMA is a 61 year old woman with chronic obstructive pulmonary disease (COPD). She has had COPD for eight years and her condition is gradually deteriorating. Three years ago she had an emergency admission for respiratory failure and was in intensive care for 3 weeks. Since that time she has been on long-term oxygen therapy (LTOT). Emma lives with her husband in a two storey home (living areas are upstairs) and is able to mobilise slowly. She has considerable difficulty negotiating stairs and applied for a State funded lift for her home. Unfortunately funds are limited and it is unlikely that this will be installed. Emma maintains her own hygiene, showering with difficulty despite adopting energy-conserving strategies.

Emma has been married to Peter for 27 years and has an adult son and daughter. Paul lives in the next suburb with his wife. Daughter Stella lives overseas with her family. Peter has ongoing mental health problems and sees a psychiatrist regularly for his condition. Peter does not interact with any of Emma's service providers and has distanced himself emotionally and physically from her and from providing support.

### Emotional and social issues

Emma's marriage has been deteriorating for several years and she feels that she receives little practical or emotional support from her husband. Peter has been highly critical and dismissive of her health condition. Emma's son and his wife are very supportive and visit twice weekly to attend to the shopping and provide social contact. Emma's socialisation is largely limited to her son and daughter-in-law. She has two friends who visit occasionally, but she has lost contact with friends from work and states that most of the other friends she previously had are "too busy with their lives" to maintain contact.

Emma's social isolation is compounded by the fact that she cannot leave her home more than once or twice a week because of the physical exertion involved in using the stairs. She enjoys going to the shops with her daughter-in-law, though her limited mobility forces her to use a wheelchair in the shopping centre. Emma has ceased to go out with her husband following an incident when he did not check her oxygen cylinder correctly and she ran out of oxygen whilst on a trip. She experienced a panic attack, became increasingly dyspnoeic and had to return home immediately. The experience has caused Emma extreme anxiety and she has had several panic attacks when outside. This has been partially addressed by teaching Emma how to manage her anxiety, including distraction and breathing techniques.

Emotionally, Emma has her "dark" and "bright" days as she calls them. She has had depression intermittently over the last 8 years and has received medication. At present she is not taking medication. Despite her limitations, Emma strives to maintain a positive attitude towards life and constantly seeks to achieve her goals, such as preparing the vegetables for dinner. The Community Health Nurse (CHN) provides encouragement and support by exploring goal achievement and assisting Emma to develop her problem-solving skills to overcome limitations. In addition to discussing challenges, the CHN ensures that the discussion also includes positive experiences of how Emma has managed her daily life and the successes she has achieved. The interaction always ends on a positive note so that if Emma has discussed issues which are distressing for her, she is not left in low spirits.

Emma acknowledges that initially she struggled to cope with the loss of her job and independence and that this made her more acutely aware of the difficulties in her marriage. Emma feels that if she was able, she would leave her husband and move back to her home state but she is unable to travel because of her health problems and feels trapped by the limitations imposed by her chronic condition. She is also learning to come to terms with a shortened lifespan. Medical staff informed her she had a year to live three years ago and she currently wavers between acceptance and denial.

The CHN has offered the opportunity of a referral to a Community Health Social Worker for counselling and this has been refused by Emma who has an aversion to the concept of 'social worker' intervention. She has also declined referral to a psychologist, possibly due to her husband's involvement with mental health services and the negative connotations this has for her. Emma is aware that these services are available to her should she decide to pursue them. However, because she was emotionally upset when discussing these referrals and vehemently opposed to them, the matter is on hold at present.

### Behaviour changes

Emma was a smoker for over 20 years but ceased after the emergency admission three years ago. She fears she will die if she smokes again and this is a powerful motivator for her. Emma states she has only experienced cravings a few times and is able to avoid a relapse by reminding herself how ill she has been with her dyspnoea and acute exacerbations. Her physical activity is severely limited by her condition. However she tries to mobilise for short periods several times a day to maintain her exercise tolerance. She acknowledges that her condition is worsening since she is not able to use her swimming pool this year to do her passive exercises due to the exertion involved in using the stairs.

Emma has received nutrition education and has changed her eating habits to avoid dyspnoea due to over-eating, and to maintain her weight and ensure good nutrition. She has struggled with her weight particularly during depressive phases when she is tempted to eat for comfort. The CHN has discussed strategies with Emma that she can adopt to constructively manage stressors rather than use food as an emotional support. The community nurse has also taught Emma how to manage relapses constructively to return to the action stage of behaviour change and to recognise that this is a normal aspect of behaviour change. Emma has also learnt to modify tasks to conserve energy, such as preparing vegetables whilst seated. Her need to maintain her independence has proved to be a powerful motivator in adapting to the changes she has had to make to adjust to her altered capabilities.

### Financial issues

Financially, Emma's chronic condition has had a considerable impact. Since her emergency admission she has not been able to work and this has reduced the household income significantly. She receives a disability pension but this does not cover the additional medical and pharmaceutical costs caused by her illness. Her socialisation outside the home is further limited by the cost of paying for her portable oxygen. Emma and Peter's standard of living has fallen significantly. They are not able to afford more than basic items. Emma would like to move to a single storey dwelling but her home is in disrepair and the couple could not afford to buy another house locally. Stair lifts cost \$10,000 (used) and she cannot afford to purchase one. The State has a subsidy scheme which arranges home modifications. Emma has had an assessment and is eligible to receive a lift. However, there are several people on the waiting-list before Emma and since only one or two are installed each financial year it is unlikely she will obtain one. This has a significant impact on her quality of life.

### Support services

The summary of services accessed by Emma is in the table on page 23. Emma's limited exercise tolerance has had a significant impact on her interaction with ambulatory services. She is exhausted by the journey to the tertiary hospital 45 minutes drive away and although her son uses a wheelchair for her, she feels unwell for days afterwards due to the physical exertion required. Emma feels emotionally drained and despondent after her unsatisfactory interactions with medical staff. The CHN has discussed strategies to assist her to interact with health professionals in a more productive way and whilst Emma has used these to some effect with her GP, she does not feel they are effective with her hospital doctors who remain evasive. She does not feel she has the emotional or physical strength to persistently challenge evasive communication strategies.

The CHN who regularly visits Emma is a facilitator for the Chronic Disease Self-Management (CDSM) course and has used the topics covered in the course such as nutrition, interacting with health professionals and goal-setting to structure Emma's self-management education. There is a local support group for people with breathing difficulties which meets monthly and the CHN has encouraged Emma to attend, but Emma does not feel she is 'a group person' and does not wish to join the group.

# Emma's story

## Implications for carers and service providers

Emma's son and daughter-in-law assume the principal carer roles. They both work and they manage to provide assistance with medical visits and shopping around their shift work and days off. This can be difficult at times. They are highly motivated and supportive carers and do not wish to have assistance at the current time. The CHN and GP have discussed support services available with Emma and her carers and provided contact numbers should they wish to access services at a later time. Emma's condition is successfully managed in the primary health care setting due to good communication between client, carers, General Practitioner and Community Health Nurse. It could be improved further by the use of the Flinders model of care planning by the primary care team and communication of this to secondary service providers as appropriate.

The complex social and emotional issues surrounding Emma require sensitive and gentle handling by service providers. It is important for the CHN to provide ongoing practical and emotional support and develop and nurture Emma's self-management skills. She needs to create a safe environment in which Emma is able to disclose emotions whilst at the same time respecting her privacy by not pressing her into courses of actions which she does not feel able or ready to deal with. Whilst the CHN has not felt threatened during her visits to Emma's home, she is aware of the safety procedures relating to home visiting and bears these in mind during visits, should Peter display agitated or aggressive behaviour.

## Notes for CCMS support people

### STRENGTHS

Tough and enduring. Strong in the face of hard times. Determined to survive and be as independent as possible. Emma has likely developed some emotional survival techniques that have protected her from the reality of her relationship with her husband and helped her to live a separate life within her current daily experience. This can be viewed as 'healthy' in the short term though concerning for its long term impacts on her mental health.

### BARRIERS

Emma is still working out what her options are in her own mind.

Does she have the energy to leave her husband? 'Better the devil you know' may be weighing against her shifting sense of her condition being terminal which means she has potentially not gained clarity about her options. Emma does not see counselling as providing any benefits to her situation and will likely be selective about whom she engages with beyond the superficial support provided to help management of her health. Digging too deep may take her to a place that is ultimately unbearable and too painful. It is likely that Emma feels this judgement from a number of health professionals who she must interact with.

### OPPORTUNITIES

Despite often feeling physically and emotionally drained, Emma has core strengths that can be nurtured.

Respect, tolerance and understanding by workers will be important to her.

Good coordinated care across service providers for both Emma and her husband will likely assist them both in managing their situation.

### IMPLICATIONS FOR CCSM SUPPORT

Support staff need to understand the dilemmas Emma faces in managing her health and how this impacts on the choices she feels she needs to make in her life.

Supporting her to build quality in her life will be a priority. Support staff will need to have the skills to not feel intimidated by the husband, yet also provide an open and safe communication environment for Emma.

Workers may feel the need to 'rescue' Emma. However, this may in fact lead to weakening Emma's capacity to remain as autonomous as possible in her situation.

By contrast, workers could put some of this tension they feel into being strong advocates for Emma, in particular, lobbying for that lift!

Support staff are likely to feel angry with her husband and protective of her. Some may feel impelled to steer her towards leaving her husband. However, this will need to be handled sensitively. Emma's self-esteem is fragile, and influenced by the sheer physical and emotional exhaustion that she often experiences, so even subtle feelings of being judged will likely be picked up by her.

TABLE 1: SUPPORT SERVICES - EMMA'S STORY

<i>Service</i>	<i>Aims</i>	<i>Frequency of Service</i>	<i>Client's view of service provided</i>	<i>Implications for carers / service providers</i>
General Practitioner consultations	Provision of ongoing medical care including management of acute exacerbations of COPD	Second monthly. More frequent if required	Recently changed to this GP 6 months' ago. Dissatisfied with previous GP, Emma felt 'rushed' and that he did not really understand her situation. This GP takes time to listen, shows interest and is willing to do home visits if she is too ill to attend surgery.	GP is gaining Emma's trust and confidence. Until 1st July not funded for the amount of time spent with her. Need for home visits in future has time and financial implications for the GP. He has a positive approach to working with CHN in providing co-ordinated care which will improve standard of primary care for Emma.
Specialist consultations at tertiary hospital facility - outpatient	Monitor condition and provide specialist input as required	Six monthly	'I see a different doctor every time. They don't know me and spend most of the time reading the notes. The junior doctors are non-committal and just fob me off if I ask a question'. Senior doctors didn't tell her delivery diagnosis for over a year after she was discharged. Feels that they are unsympathetic and have 'written me off'. Emma does not trust them and has lost confidence in the hospital system.	Limited effectiveness of interactions and interventions with hospital staff. Care viewed in terms of the medical model. Inappropriate for Emma's needs and wishes. Process of care is emotionally frustrating and destructive for Emma. It is also physically demanding. She is considering refusing to attend any further appointments because of the negative impact of attending hospital appointments.
Public hospital Emergency Department	Management of medical emergencies	As required (once three years' ago)	Emma is satisfied with the care she received	Ineffectiveness of above hospital services has implications for emergency services. If scheduled care is ineffective, this is likely to increase Emma's use of emergency department services. Care will be reactive rather than proactive.
Public hospital inpatient services	Treat acute exacerbations of COPD	As required (four times in the last three years)	Feels that the hospital does not communicate well with her GP. He is not always aware of her hospitalisation and changes to her medications. Grateful that the treatment is effective in resolving infections but Emma feels it does not look at helping her prevent further episodes.	Disruption of continuity of care. May lead to poor communication regarding changes to treatment whilst client has been in hospital. Care focus is reactive, does not assist in the prevention of further admissions.
Community Health Nursing	Provision of monitoring, education and support regarding chronic condition.	Second monthly alternating with GP visits. Client can phone during office hours with question/concerns.	Satisfied that the same nurse manages her care and maintains continuity. Feels able to ask questions or contact when issues arise. Has learnt much regarding self-management of COPD and is able to discuss issues/feelings which she is not able to discuss with family	Service funded for management of clients requiring long-term oxygen therapy. Does not provide such a service for those with COPD who do not require oxygen. Therefore client group in the end stages of COPD. Services aimed at earlier intervention would improve the quality of life and health outcomes for clients. Self-management skills should be a core competency for CHNs.
Occupational Therapy (OT)	Home assessment regarding adaptations to bathroom and suitability for installation of lift.	Two visits. No ongoing care unless referred	Satisfied with OT service. Has improved her independence and feeling of safety in the bathroom.	Maintains function and independence of client. Therefore reduces workload of carer. Referrals can be made by client or health professional.
Physiotherapy	Home physiotherapy to teach breathing exercises and strengthening exercises for legs.	Three visits. No ongoing care unless referred.	Found breathing exercises very helpful. Have improved her exercise tolerance levels and she has not had chest infections as often.	Assists in maintaining function and independence. Reduces carer input. Referrals made by health professional.
Home Care	Domestic assistance	Fortnightly service for 1.5 hours.	Satisfied with the standard of service she receives. Also provides social contact. Would like more hours of service, but these are not available due to resource constraints.	Assists Emma with household tasks. Provides social support. Funding restricts the amount of time given. Home Care Worker also provides feedback for CHN regarding changes in client's health status and coping abilities.



## Mavis's story:

# Importance of family – an Indigenous story

by Alan, *Senior Social Worker, New South Wales*

MAVIS is a 63-year-old Indigenous woman from a rural town in NSW. Mavis has had four children of her own; the eldest child is now in his late 30s and lives independently in a town 200 km away with his boys. The next oldest son has three children. However the children and their mother have lived away for some years. This son and his current partner now live at home with Mavis and they're looking after a young child. The next oldest son has approximately ten children. Of these, the oldest daughter, a teenager, lives at home with Mavis. Many of the other grandchildren come and stay for long periods of time. The youngest son has recently moved away with his partner and two children but this son has a daughter who is also being cared for by Mavis. There is a deaf member of the family who has also been staying with Mavis. He is in his mid 40s and has various issues because of his inability to communicate with family members.

Mavis has a partner who (without judging too harshly) isn't any help to her and smokes yarrndi (Marijuana) on a daily basis. Mavis has had a few jobs in her life but retired from full-time work 18 months ago. The only person working in this house is the eldest son who began working for the local shire a few months ago.

Mavis couldn't really remember how long she'd had diabetes but thought it was around ten years and that she was started on insulin twelve months ago. I asked Mavis a few questions regarding her diabetes beginning with her ability to change her behaviour to improve self-management of her health. Mavis said she couldn't think of any real changes to her lifestyle apart from having to take medications and see health staff more often: "I don't think about it (diabetes) too much – don't feel any different, as long as I take my medication I'm right. I get tired."

Of her interaction with support services, Mavis said they have "been really good for me, sometimes I forget my appointment and someone comes and reminds me. I feel well looked after." "Health service is a great place to visit."

I asked Mavis to tell me what she thought diabetes was: "Don't know what it is ... can do a lot of harm." Ideally, a person with diabetes should have an HbA1c (average blood glucose level over the past three months) of 7 or below. Mavis's HbA1c levels for the past 12 months have ranged between 8.9 and 9.4.

### Social equity issues for the person

In Indigenous communities in Australia, the health impact of low-socio-economic status, low incomes, poor living conditions, the excessive consumption of alcohol and other harmful substances, and inadequate nutrition combine to create a typical pattern of early deaths from injuries, cancers, cardiovascular diseases, and chronic health conditions such as diabetes (O'Dea, 2005). The environment Mavis and her family live in is pretty tough. Life expectancy in this town is 20-30 years younger than the rest of the population. Unemployment amongst the Aboriginal population is around 70% (not including CDEP). The evidence of the cycle of poverty is everywhere.

In this environment I wonder about a person's ability to give the time and energy that's required to manage a complex chronic condition such as diabetes. This may reflect the fact that even though Mavis had very little insight into her diabetes she was very happy with the level of care that she received. This tells me that all she is able to (or wants to) understand about her diabetes is that she needs to take her medication as ordered and see the various health professionals when asked. This also tells me that when implementing self-management tools for clients in a town like Mavis's (or any environment), they need to be flexible. I think the next step for me to be able to effectively work with clients with a chronic condition would be to use the Flinders self-management process with Mavis and determine what it is that she'd like to achieve in the next 3-6 months.

Much of this information also tells me that given the amount of grief, trauma and abuse in Indigenous communities, health providers' number one priority should be the client's mental health. I can't see how the health system can provide effective chronic disease management without placing the client's social and emotional well being first. I also wonder if the issues facing Indigenous peoples in Australia are confounded by race. It seems to me that when mainstream Australia discusses Aboriginal health, race and culture confuse the issues. All the research available clearly states that poverty impacts heavily on health outcomes. I haven't read (or seen) where race and culture are barriers to good health outcomes. If overcoming poverty were a priority, health outcomes would improve. I'm not saying mainstream society should be insensitive to all cultures and people but I don't think it should be the main talking point. For example, cultural respect should be central to all service provision but I also see that understanding the effects of poverty on individuals and communities is just as important.

### The nature and structure of the health service provision and agencies supporting the person

Things have changed in rural town. We now have six health workers who work in three teams of two. Each team has a registered nurse and an Aboriginal health worker. Two of the Indigenous health workers are mental health trained and the other is a very experienced health practitioner from the town. The three teams have approximately thirty-five clients with either diabetes or hypertension. We use a data recall system (Ferret) to manage these clients according to best practice. We then work with the visiting Royal Flying Doctor Service to assist in treatment and management regimes. Some of the programs (and health workers) on offer include: smoking cessation, access to a drug and alcohol specialist, mental health, dentist, women's health GP, endocrinologist, ophthalmologist, dietitian, diabetes educator, and podiatrist. Coordinating these visiting services to meet the needs of clients is an ongoing task. Our next major leap forward is to "bed down" self-management principles.

### Conclusion

*"Like native races of other countries, if a cure can be affected by one or two applications of a drug, the blackfellow is willing to undergo treatment; but should any prolonged treatment be necessary, then the aboriginal (sic), with his childlike mind, does not persist, but soon evades further medication"* (Anton Breinl, 1912 as cited in Humphrey and Fitz, 2001).

Commissioned by the federal government in 1911 to report on health and disease in the Northern Territory, Dr Anton Breinl, then Director of the newly established Australian Institute of Tropical Medicine in Townsville, included in his inquiries a review of the condition of Aboriginal peoples living close to white settlement. When he wrote the above comment on what would now, within the biomedical field, be termed the 'problem of patient non-compliance' he could not have known that this same concern would continue, until the present day, to dominate the thinking of non-Indigenous health professionals working within a Northern Territory context.

Moreover the racism embedded within the language of this comment and the paternalistic mentality lying behind it is, nearly ninety years later, still to be found in the contemporary commentary of a number of health professionals (Humphrey and Fitz, 2001).

### So what does this mean for Mavis?

It seems that there are two opposing worldviews. The first is the dominant, all-knowing, non-Indigenous health professional who comes from (and is part of) the all knowing dominant "main-stream" Australian society. We (health professionals) are continually frustrated by the Indigenous populations' perceived unwillingness to embrace the services we're offering. Central to the second worldview is that, until a far greater understanding of Indigenous Australian's history and culture is achieved by 'mainstream' Australia, this stalemate will continue. Also, until all aspects of non-Indigenous society work towards overcoming poverty and improving the social determinants of health, the quote from Breinl will sadly remain "relevant". Essentially this is about developing trust and overcoming disadvantage, and I see self-management principles playing a role in this. By more meaningful conversations around clients' hopes can we then start to develop a clearer picture of what's important (and therefore some of the barriers) toward effective chronic condition management.

# Mavis's story

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## Notes for CCMS support people

### STRENGTHS

Mavis is the head of her family and her home is a place that provides security and stability for them. Mavis appears to have a positive view of life, despite the many pressures on her life and in her environment. She is a copier.

### BARRIERS

Mavis's priorities will not likely be the same as the health professionals' priorities. She accepts having limited knowledge of her health condition.

### OPPORTUNITIES

Be there and be flexible. Mavis has trusting relationships with her current health service providers.

### IMPLICATIONS FOR CCSM SUPPORT

Matching support with the reality of Mavis's daily experience will be important. An holistic approach is unavoidable. Know and understand her first; provide advice second. Work with her to understand what her priorities are. Address poverty. Provide basic support and enlist constructive help to navigate service systems. Do this with Mavis and let her share, lead and speak for herself. Be the mediating influence that helps other health care providers to understand the person who Mavis is.

# The importance of transport

by Linda, *Community Health Nurse, Rural Community Health Service, Victoria*

**BILL** is a 69 year old pensioner who has lived on the rural fringe for most of his adult life. His health problems include chronic heart failure (CHF), poorly controlled insulin dependant Type 2 diabetes, prostate cancer, osteoarthritis, chronic leg ulcers and alcohol abuse. Bill lives alone. He is divorced and has three adult sons and three grandchildren. His driver's license was recently suspended for three years for drink driving offences. Services in place to support him include home care for four hours fortnightly. His GP directs the care of his health conditions and is approximately 800 metres away. An Occupational Therapy assessment was undertaken two years ago.

During the last two years Bill had been admitted four times to a public hospital for exacerbations of his CHF. The hospital has a Hospital Avoidance Risk Program (HARP) Chronic Disease Management CHF Outreach Program which is a partnership with local Community Health Services. Clients who present to the emergency department with CHF at least once in the previous 12 months are eligible for inclusion in the program. The outreach service provides home visits for education and monitoring. They also run a weekly CHF exercise program. There are systems in the acute sector that trigger referrals of clients like Bill. He met all of the criteria however missed being referred to an appropriate program that would provide support to him to prevent exacerbations of his CHF. There were a number of other resources and services he could have been referred to or accessed during these admissions, such as referral to Royal District Nursing Service (RDNS) for wound care under the Post Acute Care program or a Diabetes Educator's review. Bill was also given a number of outpatient appointments which he failed to attend as without his license he couldn't get there. On each of these occasions his appointment was rebooked and sent out to him in the mail. Once again the system failed to pick up his non attendance as an alert for further investigation or referral to a CHF Liaison nurse even though several of his appointments were at the CHF outpatients clinic.

In October of last year Bill self-referred to the Community Health Service for an exercise program hoping to lose weight and get fit.

At our first appointment Bill presented with:

- Chronic leg ulcers which were dressed 2-3 times per week by his GP. He often only attended once per week (as in this instance) due to transport issues (license suspension) compounded by his reduced exercise tolerance as he couldn't walk 800 metres. The dressings were in need of changing and very soiled.
- Bilateral, grossly oedematous lower limbs and ankles.
- Uncontrolled Diabetes with BSLs ranging from 10-18 when he randomly did them.
- A daily alcohol consumption of six stubbies.
- His toe nails and feet were in a much neglected state and in need of attention.

Interestingly none of this was a serious concern to Bill as he "could live with this" until his fitness returned and he could walk to see his GP.

Fortunately Bill could be referred to the CHF outreach program from the Community Health Service. He was also eligible for the Chronic Disease Management program where the Flinders Model could be used with him. He was very happy to accept whatever was recommended if it would assist him to get fit and lose weight. The supported CHF exercise program, where transport can be provided to assist people to and from the sessions, allowed bill to exercise and socialize with heart failure clients. The CHS could also provide benefits for his Diabetes management by referring to a Diabetes program. The outreach nurse could monitor his out patient appointments and ensure he could attend by arranging transport options for him. The clinics would report the care changes directly to the registered nurse and would also liaise with the GP who coordinated his care. Bill was also referred to RDNS for management of his leg ulcers in the home. A referral to an alcohol counsellor helped a lot with his alcohol usage.

## Bill's story

Over a three month period Bill made significant improvements to his health and lifestyle. The exercise program provided both physical and social opportunities for Bill. His Diabetes and Heart Failure became under better control with adjustment and monitoring of his medications and education. He came to understand the relationship of his medications and his oedema which assisted the healing of the ulcers. Bill achieved his goal of getting fit and losing weight.

The acute sector has many intervention programs that offer huge benefits to clients with a vast array of chronic illnesses. These programs attempt to reduce the person's presentations at the emergency department of public hospitals. They rely on the referral process to be activated at some point in either the emergency department or on the wards. In the case of Bill who 'slipped through' on four occasions, it highlights the deficits of the system in the acute sector. However it also demonstrates the benefits of the outreach program in the community by providing another referral point for clients. It could be further strengthened if GP clinics and practice nurses could have an increased awareness of the vast hospital intervention programs and community services to provide another referral point for clients like Bill who are missed in the acute sector but whose health and quality of life could be significantly enhanced.

## Karl's story:

# 'If it's still running, don't look under the bonnet!'

by Margaret, *Senior Physiotherapist,*

*Children, Youth and Women's Health Service, South Australia*

I would like to re-introduce a close friend of mine, whose care plan I completed a few months ago.

KARL's situation, like life, has moved on from that time, with some changes made, so it is timely for critical reflection on his perception of his chronic conditions, and his experience of managing them. Along the way I will explore some of the formative influences on his viewpoint and belief systems about his chronic conditions. These influences include culture, gender, generation, socioeconomic status, and his life experience as a survivor of war, and as carer to his frail-aged mother. Notions of resilience and optimism, and implications for health team workers and loved ones supporting Karl's chronic condition self-management, will also be addressed.

### Relevant biographical details

Karl is a 79 year old senior pensioner retiree and homeowner, who lives with his partner of 13 years. Karl has two grown up sons, several grandchildren and great-grandchildren, and two sisters, all living in Adelaide. He enjoys frequent contact with his sisters and sons. Karl was a child in Berlin during World War 2, surviving the destruction of his home city. He immigrated as a young adult to South Australia. Karl enjoys doing community volunteer service twice a week as a "spare partner" and assistant tutor at ballroom dancing classes. This he has done for 19 years, and he regards it as essential to his social life and physical fitness. He shares his passions for dance, soccer, travel, people and current affairs with his partner. He excels at cryptic crosswords and writing poetry in two languages, and is a self-taught home handyman and model railway builder. He maintains a lively correspondence with friends and extended family in Germany. Karl enjoys lots of strong coffee, uses alcohol sparingly, and smokes 4 to 6 cigarettes a day. Joyful and industrious, he paces himself through his busy days with catnaps. "Everything in moderation" Karl says of himself. "I seem to know my limits."

### Socioeconomic status

Karl's sole income is his aged pension. He tells me he cannot afford to be sick! He does not have private health insurance. "So far, so good," he says. Baum (2002) and many other social researchers make the point that access to good

health care, and chronic condition self-management, are much harder on a restricted income. Deveson (2003) acknowledges that resilience is harder to practice or learn if basic economic security is not in place. Karl's GP or partner may well begin tactful discussions with him about the need to explore some options for at least basic hospital cover privately for the future, given long waitlists at public hospitals, and given that most people have their greatest need for medical care in their senior years. Karl is debt-free and very frugal, and manages to save from his pension for occasional trips to Germany, so \$1,000 a year for hospital cover may not be totally out of the question. Social inequity disadvantages pensioners in a myriad of ways (Baum, 2002).

### Karl's chronic conditions and his mode of self-management:

For the last ten years, Karl has had generalized osteoarthritis, gradually worsening, and now causing pain most days. He takes glucosamine and cod liver oil, and uses analgesics sparingly as Ibuprofen gives him reflux and Paracetamol causes constipation. Karl's worsening arthritic pain has in the last few years had a side effect of hyperalgesia, whereby he experiences previously pleasant sensation such as massage or light touch as painful. "It starts out pleasant, but within a minute or two it becomes really painful, and I have to ask my partner to stop". Varicose veins in both legs cause him pain at times. He wears one surgical stocking. He takes Cartia daily. Mildly high cholesterol levels do not worry Karl unduly. His blood pressure is usually within acceptable limits and does not require medication. Karl exercises regularly, with his dancing twice a week, and walks a few days a week. He is aware of the National Physical Activity Guidelines for his age group (DOHA; 2005), uses a pedometer, and believes he gets reasonably close to adequate levels most weeks. He does not wish to try aquatic therapy for his arthritic pain, as he has trouble getting his elastic stocking on and off, and he is not fond of pools.

### Karl's personal experience of chronic illness fascinates me!

He is stoical, cheerful and optimistic. His attitude can be summed up in a couple of memorable 'Karl quotes': "My chronic condition is happiness!" He believes in the power of positive thinking and of a daily counting of blessings. He says that he feels richly blessed to have survived the war with his family intact, to have had the opportunity to bring his sisters and mother out from Germany as migrants, to have a loving family and partner, his own modest home, an aged pension, and robust good health. He is delighted that people he meets think he looks a decade younger than his age. He finds joy and beauty somewhere in every day, even when in pain. He is deeply grateful to his adopted country and proud of the best of his German culture. Karl's capacity for thanksgiving, his conscious decision to view any cup as half full rather than half empty, and his deep sense of connection with loved ones, community and life itself are all ingredients of resilience (Deveson, 2003), a quality which the same author describes as "continually prompting regeneration and renewal" (p.267), and equipping a person to cope with life's challenges.

These cultivated habits of mind and heart have equipped Karl to age well. Deveson (2003, p192) cites Dr George Vaillant (1993), psychiatrist, Harvard professor and researcher of successful ageing, who has "identified four human qualities which help older people become 'the happy well and not the sad sick'. The first is a future orientation. The second is a capacity for gratitude and forgiveness. The third is the capacity to love, and to have empathy for others. The fourth is the ability to interact and connect with people," plus a refusal to adopt the self-image of victim. The world, warts and all, is perceived as a safe place to be!

Vaillant (1993) based his comments on his studies of the lives of more than 800 people over six or more decades. He concluded that good health is as much a state of mind as it is the absence of disease. Again cited by Deveson (2003) Vaillant described "An ability to experience the biological ravages of time without actually feeling unwell. In other words, people can present symptoms of ill health without believing themselves to be unwell" (p.192).

Vaillant could have been describing Karl's viewpoint! He does not see himself as having chronic disease. Rather, he says that his symptoms are unavoidable nuisances of ageing, shared by most people of his generation. I detect some impatience and embarrassment on Karl's part

towards discussion of the topic, and distinct resistance to having more than basic medical surveillance. He regards illness as a private matter and prefers to be alone when unwell. Karl regards his body with the same "tough love" that he lavishes on his 1952 original Morris Minor. "If it's still running, don't look under the bonnet!" he says of both "vehicles" - another definitive 'Karl quote'.

As well as this conscious decision on Karl's part to focus only on wellness, could there be unconscious beliefs that forbid him from admitting to any frailty? Are culture and life experience at play here? "How many injunctions to bear pain do we receive throughout our lives, starting with childhood?" Deveson (2003, p176) asks, giving examples of exhortations for us to cheer up and stop crying. This is true for both genders and across many cultures. The German cultural tradition for centuries has valued and insisted on valour and stoicism (witness the heroes of Germanic and Nordic folklore), and never more emphatically than during Karl's childhood. Growing up under the Third Reich, all Karl's generation were subjected to strong indoctrination at school, in all youth groups and media about survival of the fittest, and the dire fate of the halt and the lame (Roland, 1993). Karl describes having heard the Fuhrer addressing a Hitler Youth rally, exhorting all sons of the Reich to be "tough as leather, hard as Krupps steel, and fast as whippets". This slogan was then adopted by his teachers. A tall order for small boys! Karl told me that for survival, any self-doubt about whether or not he himself belonged to the master race gene pool and any reluctance to engage in tough "masculine" drills at school, had to be hidden from the gaze of authority figures outside his family. Two evacuations from Berlin as a young boy, to live for months in country barracks with hundreds of schoolboys, taught this sensitive lad to keep any "weaknesses" like homesickness or illness totally private. Semi-starvation in Berlin during the Occupation years also strengthened stoicism. Due to his parents' private opposition to the Fuhrer, and his loving family, Karl managed to escape the worst of the Nazi indoctrination. Nevertheless, he is prepared to allow that his reluctance to admit to any physical frailty may in part be a vestige of his youthful experience of his birth culture and war.

Karl tells me he believes that birth order as the firstborn, older brother to two sisters also influenced his self-perception of health and stoicism. His parents encouraged him to be the role model for his sisters, happily swallowing the weekly dose of cod liver oil which children were required to take as a tonic. Karl can remember

demonstrating the procedure regularly to his sisters, ignoring the unpleasant flavour, and play-acting smacking his lips with gusto, to give the girls courage to take their own dose. Karl remembers this as one example of the duty of care and chivalry he was taught to feel for his little sisters, and by extension, for all womanhood. This is the gentler face of his stoical conditioning, but it required him to downplay any personal frailty, for the sake of others – a habit of mind which persists to this day.

Men typically have more difficulty admitting to, and self-managing, chronic conditions than do women (Gibbs, 2003), so his gender can be added to Karl's cultural background as a challenge to his effective self-management. An implication for agency workers is that Karl finds it easier to relate to his male GP than to female doctors. As well as his current use of the Flinders model, Karl may well benefit from a peer-support model of CCSM, namely the Stanford course, where his group comprised male age-peers, especially if also from a Central European background.

### Optimism: a two-edged sword?

Anne Deveson (2003) makes the point that resilient life skills that help a person in one situation or environment may hinder them in another. Can Karl's admirable optimism ever be an impediment to his effective CCSM? His determined "cup-half-full" and "grin-and-bear-it" approach at times prevents him from acknowledging any negatives or problems. At what point does "grin and bear it" become "head in the sand"? An example is his hyperalgesia and its impact on his relationship with his partner, and I will return to this example later in this paper. His brand of optimism may also impede his seeking medical investigations. When Karl says: "If it still runs, don't look under the bonnet", this suggests that he fears that even simple investigations may reveal some sinister, or far-reaching health problem. Karl readily acknowledges this belief, and extends the analogy by pointing out that when one takes a car with a simple fault to a mechanic, they invariably find more and more things to fix!

Karl also describes his experience of being his mother's carer for her final six years; a loving role he treasured. His mother had advanced peripheral vascular disease and associated conditions, more and more of which were revealed on every investigation. This culminated in a foot amputation, then a recommended amputation of the other foot, at which point, she died.

Practice workers, carers, and Karl's partner need to walk a fine line between endorsing Karl's optimism as a life-enhancing talent, while still gently encouraging him to engage in appropriate health surveillance, investigations and treatments. It seems to me that Karl fears that by acknowledging any health concern to himself, he will undermine the positive thinking and resilience that have stood him in such good stead all his life, and leave him pessimistic and powerless. Anne Deveson (2003) is again helpful, when she distinguishes between realistic hope and illusory hope. Resilient people, she says, recognize when to abandon illusory hope (the impossible dream), in order to move on to a more realistic form of optimism. This distinction could be discussed gently with Karl. It is illusory to hope to have the body of a twenty year-old at age 79, but it is realistic to expect that he will continue to have the skills and support to cope with any new challenges that arise in his ageing body.

Perhaps the car analogy could be turned around to support a health-promotion, or preventative-model, approach? We could suggest to Karl that some minor maintenance or spot-checks done regularly could forestall the development of more extensive problems! For example, one can applaud him for keeping his annual or twice-yearly GP visits for flu shots and to monitor his blood pressure, and vision screen for safe driving. It could then be suggested to Karl that he consider being a little more frank with his GP about the extent of his arthritic pain (rather than down-playing this stoically), in order to open up a discussion of best-practice for management of OA, and prevention of further joint damage and activity restriction.

Both his joint pain and the general hyperalgesia have become significant issues, impacting on Karl's enjoyment of exercise and on his physical relationship with his partner. Karl's reluctance to discuss this with me or his partner may also reflect cultural, generational and gender-based taboos re women's enjoyment of physical intimacy. The fact that, subsequent to his care plan, Karl did in fact discuss this with his partner, is very encouraging, and indicates his willingness to change for his loved one's sake. The compromise they have embarked on is to go out dancing together more often, a form of intimate touch they both enjoy, and that, Karl reports, is not stymied by his hyperalgesia. Indeed, the music and movement of the dance appear to generate endorphins for Karl, which block his pain receptors.



# Karl's story

## Capacity for change

Being the resilient, creative person that he is, Karl has made many changes in the four months since we wrote his care plan together. As a result of our discussion, Karl was motivated to explore his multiple and worsening joint pain with his GP, and clarified which type of arthritis he has, at least symptomatically. He did carry out the dancing strategy, and was able to re-negotiate with his partner re their physical relationship to their mutual satisfaction. Having had a recent health scare, he is now considering private medical insurance. He is not yet ready to further explore management of his hyperalgesia or his shoulder joint pain. "One thing at a time" is his preferred option – a reasonable request! I note that the motivator for all these changes is Karl's love of his partner, who supports him in all these explorations.

## Summary

I am very grateful to Karl for sharing his story so intimately, and to his partner also, and they have taught me so much about the influences of cultural, gender, generational and life experiences on belief systems and attitudes to health and life. I am inspired by Karl's history and viewpoint and his capacity for positive change. I hope I am doing as well as he when I approach my eightieth birthday!

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## Notes for CCMS support people

### STRENGTHS

Resilience personified.

Karl is in a highly respectful and 'solid' relationship and has many family supports. They contribute to his quality of life and he equally contributes to theirs.

He appears to know his limitations and maximises what he can do. He follows his own advice diligently, yet doesn't overly focus on illness. The cup is always half full, never half empty. Karl is stoic, philosophical and uses humour to maintain perspective. He knows that life has both ups and downs and both are necessary for life.

### BARRIERS

His positivism may mean that others overlook when he is truly struggling.

Depression is unlikely, however it may be difficult to detect and he may hide it well, if it develops. He is a little vain, likely to put on a brave front and is stubborn after all!

As a 'coper', he will soldier on and minimise his needs, so early detection and action on further complicating issues may be delayed. Support people will need to 'read' the subtleties of Karl's interactions.

He is a highly intelligent and cryptic person. He'll listen but it is another thing whether he will follow advice that does not fit with his views of his situation.

He has had much time and experience developing a unique coping style which has served him well. Alternatives and the skill of who delivers them will be questioned.

### OPPORTUNITIES

Karl seems highly adaptable to new challenges, is very buoyant, as shown by his past experiences and approach to life. Therefore, this could be a point of engagement and acknowledgement by others.

Karl likes to problem-solve.

### IMPLICATIONS FOR CCSM SUPPORT

One challenge for workers is showing Karl that they have useful suggestions that will add benefit to what he already knows and does for himself. Part of this process will be allowing him to lead, reflect, select and incorporate the parts that fit with his overall style and core beliefs about illness and how it is accommodated into life. He will not be passive in the process.

## Alan's story:

# Opting out of the health service merry-go-round

by Deborah, *Clinical Nurse Consultant - Heart Failure, South Australia*

ALAN is a 57 year old invalid pensioner who lives alone in public housing. He presents with evidence of self-neglect; poor hygiene and is unkempt. His unit is in disarray with empty food packages distributed in piles around the small lounge/kitchen area.

Alan immigrated to Australia with his parents and older brother in the 1960s with the hope of escaping an impoverished lifestyle in England. Alan's father secured work in a factory as a process worker and his mother worked as a kitchen hand in a café. Not long after arriving they were able to purchase their own home. When Alan was 14 years of age his father was tragically killed in a car accident. He recalls the bank took the house back when his mum could no longer meet the payments. They moved around in rented accommodation before finally securing public housing. Alan left school at 15 years of age and commenced work as a press operator in a factory. Alan was married three times and is currently divorced. He has no children from any of his marriages. His brother died five years ago of lung cancer and is survived by one daughter with whom Alan has no contact and has no idea where she lives. Alan's mum is in a nursing home in a secured unit, suffering from numerous ailments including dementia. She never remarried. Alan has few friends, no interests or hobbies. His only social activity is his daily ride on his gopher to the shops.

Alan has a history of chronic heart failure, Type 2 diabetes, type 2 respiratory failure, peripheral vascular disease, chronic leg ulcers, ischaemic heart disease, angina and obesity. Alan has been obese for as long as he can remember and has had diabetes for more than 30 years. He cannot recall how long he has had cardiac problems but knows it has been probably 15 years. He accepts the peripheral vascular disease and the chronic leg ulcers are related. Five years ago Alan discovered he had a respiratory problem and heart failure after an Intensive Care Unit (ICU) admission due to acute pulmonary oedema. He has required a hospital admission each subsequent year for acute pulmonary oedema.

Alan has been on an invalid pension for 12 years. He has never exercised and financial difficulties have limited his choices for food over the years. "It is cheaper to eat packaged food than it is to eat fresh". Alan has never smoked and rarely drinks alcohol.

Surprisingly Alan has had little to do with the medical fraternity in spite of his co-morbidities. He had relied heavily on his General Practitioner (GP) over the years building up a good therapeutic relationship. However his GP retired 15 years ago, leaving junior doctors in his place. Alan has no confidence in their ability to manage his care and believes he is doing just fine by himself. Alan has not attended his GP for any complaints for 10 years; his only reason to attend is for prescription issues. Alan has never seen an endocrinologist or diabetes educator and it is unclear if he has ever been referred. Since commencing on home oxygen 18 months ago a respiratory educator visits him in his home three-monthly. This visit includes chronic respiratory disease self-management education. Part of the home oxygen therapy is the requirement for regular assessment by a respiratory physician. This has not occurred and Alan continues to fail to attend. Looking on Alan's records he has had a number of specialist appointments where he failed to attend. He has a district nurse visit him to do his leg dressings weekly and he attends an outpatient vascular clinic. The only other service Alan receives is one hour once a fortnight for cleaning. During Alan's last admission he was referred to all available allied health. A number of recommendations were offered such as showering assistance but this was refused by Alan who found the idea intrusive. Alan also refused Home Support Program (HSP) help for shopping as he likes to choose items in the supermarket himself. Alan did not want people influencing what he bought. Alan was also advised that his GP could apply for access card vouchers on his behalf. He did see his GP for vouchers but was disappointed when he realised how much he still had to pay. Alan stated he did not attend unnecessary appointments because he could not afford them. He believed the vascular appointments were necessary and was prepared to pay what was required to attend those. For all the appointments he failed to attend no follow-up phone call was instigated to ascertain a reason for the absence.

## Alan's story

Alan has limited education, a lack of inclination, minimal financial resources to support self-management and little faith in the medical system. However he was receptive to education, specifically symptom recognition of his respiratory condition, his heart failure and his diabetes delivered to him in his home. It is difficult to see if the medical system has failed to provide opportunities for improved management such as diabetes education or whether inadequate access to financial resources which would support better management is the barrier. Either way through the maintenance of pride and for financial survival Alan's health has not been adequately managed. All of Alan's admissions were the result of not recognising his dyspnoea was related to heart failure and this area was never addressed, resulting in reoccurring admissions. The only exposure to self-management strategies he has had has been the respiratory nurse. The previous nurses from the respiratory nursing unit offered only chronic self management strategies for their area of practice. Surely The time has come in which the whole chronic condition management program must look at co-morbid management or identify the barriers to self-help. Every opportunity must be viewed as an opportunity to promote self-management, however arguably resources must be rationalised for both the patient encounter and for the health system. The patient with co-morbid conditions cannot afford the financial burden associated with multiple medical visits and the financial cost of the pharmacotherapy is often also prohibitive for the patient. We need to be mindful when we organise appointments of the cost incurred by the patient and provide at least a courtesy call to enquire as to why the patient failed to attend. If someone had enquired earlier they would have discovered his reason for failing to attend was he could not afford the transport, even with access cab vouchers. Perhaps a viable adjunct therapy would be home visits by trained people such as nurses in chronic condition management per se rather than multiple people trained in only one area making it necessary for patients to have multiple encounters with medical staff.

Notes for CCMS support people:

### STRENGTHS

Alan is pragmatic.

He weighs up what he feels is of value to him.

### BARRIERS

Alan is very largely alone in the world. This has been his experience for some time. He will choose who he lets in.

He is not likely to trust others readily. He has 3 failed marriages which makes this developing trust less.

Life is likely to be about limits rather than opportunities.

### OPPORTUNITIES

Multiple opportunities exist to provide Alan with information about his health conditions. The trick will be how it is delivered. He is a pragmatic, no nonsense person, so will likely appreciate a 'straight up' approach that allows him to weigh up priorities for action that fit with him.

He has let health professionals into his life and his home when he has seen clear benefit and need to do so. This is a bonus that can be built upon.

### IMPLICATIONS FOR CCSM SUPPORT

Support with transport will be important.

Respect for Alan as an individual and for his privacy will need to be considered by health professionals.

It would be tempting to offer a lot of services and information in a rush, without making sure that Alan is alongside the worker and moving forward at the same pace.

Alan has shouldered much responsibility since he was an adolescent. This means that he sees himself and the driver and ultimately responsible for his health, not workers.

## Kimberly's story:

# Growing up with a chronic condition

by Angela, *Head Physiotherapist,*

*Children's, Youth and Women's Health Service, South Australia*

KIMBERLY (Kim) is a 15 year old living with cystic fibrosis (CF) the most common genetic chronic disease in Caucasians. She was diagnosed with CF in the first week of life and has the most common genetic mutation (delta F508). As a consequence of CF, Kimberly has recurrent chest infections and problems with digestion both of which require a large number of medications, oral, and inhaled when stable, as well as intravenous (IV) when she is unwell. It is recommended that Kimberly perform daily chest physiotherapy and participate in aerobic exercise to clear thick mucous from her lungs and that she eats a high fat, high calorie diet requiring pancreatic enzyme supplementation (oral capsules).

At birth, Kim suffered from meconium ileus (bowel obstruction) requiring bowel resection and a temporary ileostomy which was reversed when Kim was seven months old. Subsequent to these gastrointestinal issues, she did not require a hospital admission until age four and then again at age seven. Since 2000, Kim has had between one and four admissions per year, occasionally for bowel problems, and more commonly for chest exacerbations. Kim attends the Women's and Children's Hospital (WCH) every two to three months for outpatient check ups. Kim would be described as having mild CF, as a reflection of her current lung function (greater than 100% predicted) and the number of admissions for IV antibiotics per year (currently averaging three per year). She lives with her Mum (Linda), Dad and older sister in the Riverland of South Australia and attends the local high school. She is a keen dancer.

Both Kim and her mother were interviewed for this case study. Kimberly and Linda were both happy to have their names used in this text.

### Balancing CF with having a "normal" life

Kim was asked to describe how she balances all her treatments and requirements of CF with being a teenager. She reported that balancing was "tricky" especially when she gets sick (lung disease exacerbation) because this will mean an admission to hospital. She needs to consider the timing of the admission, based on the severity of her exacerbation, and what commitments she has over the next few weeks at school, with dance and social life. She reports that the balance is easier when she is "well". She can modify timing of treatments with school, homework, dancing and social commitments, modify when to have inhaled medications and she also considers what treatments to delay or skip based on how well she is at the time and what other activities she needs to fit into her day. Kim's mum helps a lot with organizing her and motivating her. Her Mum understands her health well and assists her in making choices such as when to miss school, when to do treatments, when to be admitted to hospital. Her family encourages and supports her to do treatments because they all know that it will help her health in the long run. Keeping up with her friends and trying to be as normal as possible are Kim's other motivators. She has some close friends who encourage her to take her medications and who can see if she is struggling and who support her to stay healthy.

Linda uses the "cross that bridge when we come to it" approach in dealing with the demands of having a daughter with a chronic illness. In the past she has valued support and guidance from other CF parents and now proactively seeks out information regarding CF on the internet and through her nursing studies. She tries to focus on the positives such as Kimberly's current health status, on better treatment options (physiotherapy and antibiotics) and remains hopeful that there will be treatments that either maintain what Kimberly has got or provide her with a better quality of life. When asked how Linda continues to be motivated to support Kimberly, she reports she is "just that kind of person"; some parents have motivation and some do not. Linda thinks that the positive feedback she gets from her daughters and from her girl guide group motivate her to continue with a positive, motivating attitude. Linda is motivated to support Kimberly because she wants to be able to say, "I have done the best for Kim".

## Kimberly's story

Linda knows the long term benefits of effective treatments on a day-to-day basis will have a positive effect on Kim's health in the long term. Linda regularly has to juggle commitments to Kimberly in hospital with the demands of her husband and other daughter, her own work and her nursing study.

### Adapting to changes

Kim understands her health is changing as she gets older. She knows she is a bit sicker because when she was younger she didn't need to come to hospital and now she does. At the moment she adapts well by doing school work while in hospital. Kim is often presented with new treatment options such as physiotherapy. She thinks change is good, it adds variety, making treatments not so boring. She monitors her symptoms and adapts her treatments to fit her current symptoms. For example, when she is unwell she might choose to get her Dad to do a percussion treatment, and if she is well she might skip a nebulised medication or substitute treatment with a dance class. Kim has to make choices about the way her IV antibiotics are administered. She is currently adapting to the idea of having a permanent venous access device (port) surgically implanted. She wears leotards at dance classes and the port will be visible - a big consideration for her. Kim often has to communicate with new staff involved in her treatments. She describes the benefits of having regular staff to help her feel at home, and that she does not feel as close to new staff and that they ask boring questions.

Linda reports that early on she has coped with Kim's CF by being incredibly vigilant, by not missing any treatments and by following strict infection control guidelines such as not allowing Kim to socialize with other children until she was over 12 months old. This was to the detriment of Linda's mental health; Linda suffered from post natal depression. Linda adapted her coping skills as Kim grew older by addressing her own mental health, by using medication and attending numerous "mind" courses. Linda describes how she has had to adapt to Kim's developmental stages by initially taking full responsibility for treatments then transferring most of the responsibility to Kim as she gets older. This has been a challenging transition for Linda to hand over responsibility to Kim.

Linda describes how her perception has changed over time. In the early years, she thought Kim was going to die if she got a chest infection; now Linda focuses on what Kim can achieve. As Kim's health continues to be quite stable and her independence increases, Linda can now "get back into my own life". She is studying nursing and works part-time. However these new activities require more of a juggling act, finding time to study, to come to Adelaide for outpatient appointments and inpatient admissions, getting others to cover for her at work and negotiating with her husband and elder daughter to spend time with Kim whilst she is in hospital.

### Concerns and benefits of having CF

Kim was questioned about her concerns about having CF. She said that as she gets sicker it is harder for her to keep up with the other kids at school PE (physical education) and that she is not as fit. She has trouble missing things at school when she is hospital. She gets assistance from the WCH school to contact her teachers at her local high school, to get work sent to her, but that the paperwork she gets from the school is not like sitting in on a lesson. She thinks about when she is older and how her CF will influence her career choices. She considers how well or sick she will be when she is older. Kim has a needle phobia which causes her large amounts of distress during hospital admission. She reports how one of the doctors has gone out of his way to teach her self hypnosis which will help with her phobia and that she feels good that he wants to help more than just her lungs. She also mentioned that she gets a bit self conscious when she has an IV line in and people look at her.

It is not really possible for Kim to be treated in the Riverland. The doctors know a bit about CF, but don't really know how to treat it and don't have the equipment. She would be happy to go to a Riverland hospital if they knew what they were doing. Her friends could visit her if she was in a local hospital. Kim reported that traveling was difficult. She needs to have permission to have drugs and needles on the plane and in the hotel and she requires extra luggage allowance. Traveling takes a lot of organizing. Holidays don't mean holidays from treatments - they come along too! When away she has to consider what she eats and where she goes just in case she catches something. She can't attend the local swimming pool due to risk of infection which is "the thing to do" in summer in the Riverland with her friends.

CF makes it more difficult for Kim to have sleep overs at her friends' houses because of the need to do treatment and the equipment needed, so she will often go home early to do treatments. She feels different to other students at school camp because she has to do her treatments and take equipment and because her Mum usually attends to help the teachers who don't know much about CF. Kim thinks it is off putting for her boyfriend and class mates to hear her coughing up lots of sputum. She reports feeling frustrated at times that she looks so normal, so people don't take her seriously when she says she has CF and that she has a serious illness. She thinks it is unfair that people who look sick get more sympathy and more fund raising money. "You have CF for life and there is no cure" (compared to children who recover from cancer).

Kim reports that CF has made her a better person; she can take care of herself, eat healthily and keep fit. CF has shown her how to get the most out of life, to enjoy each day and appreciate more things in life, in particular being healthy and being able to go to school. Linda worries about how Kim handles everything. In particular she knows Kim wants to be a mum herself and worries whether this will be possible. Linda describes how her daughter's CF makes it hard to plan ahead and that the family needs to be flexible. Kim likes someone from her family to be with her while she is in hospital. Her parents need to find extra money for take-away meals during that time, and also extra money for accommodation. She reports that her parents need to buy new cars regularly and get their cars serviced frequently due to the number of kilometers traveled to get to the hospital. Kim's family must purchase CF medications and equipment.

### Implications for family members

Both of Kim's parents resigned from their original jobs once Kim started requiring more hospitalizations. Her dad bought a fishing license and mum got casual work so they could work flexible hours to allow time to attend to Kim's day-to-day treatments and for trips to Adelaide for visits and admissions. Kim thinks her illness has influenced her mum's decision and ability to study nursing. Kim thinks her mum has changed lots since she was diagnosed with CF, her mum has learnt to deal with doctors and nurses and is very organized and motivates Kim to be as healthy as possible. Her mum knows a lot about CF and about Kim's health. Kim thinks it would be hard for her family to see her sick and in pain and that they miss her when she is in hospital.

Dad is on his own a lot because he has to keep working. Kim knows her family have to juggle a lot; work, attending hospital, helping her with her treatments. She sees some other CF kids whose parents don't visit and she feels lucky that her parents are supportive.

Kim's older sister is always there for her, caring for her, helping with treatments. She knows it is hard for her sister to see her in pain. When they were younger, her sister found it hard that Kim could eat all the junk food she wanted and that Kim "gets everything". Kim knows that her CF has influenced her sister to study nursing. Linda talks about how she balances spending time with both her daughters and how earlier on, she spent more time with Kim and now as the girls are older, she is spending more time with her elder daughter because they are both studying nursing. She thinks that both girls now have a good perspective on what the other feels with regard to attention from their mum.

### The future

Kim is fine knowing she will have CF for the rest of her life, and can't imagine not having CF. She would love to see a cure or something big to help with her CF but she doesn't pray every single day, but if something happens (a cure) then that'll be great, but it is not something she worries about. She has thought about finishing school, maybe going to university to be a dietitian and would love to travel and move out of home. She knows she has options for her senior schooling (in terms of splitting up Year 12 over two years) but is not considering them currently because she is coping well with her school work. She recently talked to her Mum about lung transplantation (one treatment option available to CF patients once lung deterioration reaches a certain level (less than 20% lung function). She knows she is currently well so doesn't think about it much, and believes that if she keeps well by doing her treatments she won't need a transplant until much later. Kim would love to have kids of her own, but it doesn't really bother her if she can't.

### Practice implications for the WCH and workers

Managing a chronic illness in a rural area adds a number of burdens to patients with chronic conditions and to their carers. These include financial burdens, time, and access to skilled health care professionals. There are clusters of patients in the Riverland, Yorke and Eyre Peninsulas and the South East of South Australia. These patients would benefit greatly if an outreach clinic was provided by the WCH.

CF patients have better health outcomes if they are managed by a CF specialist centre, so the outreach clinic would need to be staffed by WCH personnel. The WCH provides a "hospital in the home" service where patients' parents can administer IV antibiotics at home after appropriate training. This service is only available to patients who live within a 30km radius of the hospital. Rural CF patients would benefit if this service was available to them. The introduction of telemedicine in the CF clinic could also potentially reduce the burden of travel to Adelaide for these rural clients.

Linda identified lack of information and support in the early years of Kim's life. The WCH currently only has part-time staff; a CF clinical nurse, a psychologist and a social worker who deal with these issues. WCH staff need to ensure they have up to date knowledge about CF and the skills and time to be able to impart this knowledge, such as information regarding lung transplantation, pregnancy and careers. Creating links with other families and CF organizations would also potentially improve this problem. Schooling is identified as another burden. Forging better links between the hospital school and the patient's school and creating an environment on the hospital wards to promote schooling would be an advantage for CF patients. Finding treatments that are less time consuming, boring and that improve or maintain health would add to the patient's (especially in the short term) and carer's quality of life. It is crucial that WCH staff are aware of current research and use the principles of evidence based practice. Kim and Linda both gave eloquent examples of how they adapt to changes in health, in treatments, and in the way they cope. Health care professionals need training in facilitating adaptation. Families with CF have to fight for appropriate financial assistance from the government, such as travel expenses, medication and carers' allowance, and recognition of their life limiting illness by the community as a whole. If the impact of time consuming and burdensome treatments was recognized by the community and the government, patients would be relieved of another burden.

### Summary

Kim is a teenager with a chronic illness who is developing her independence in the management of her chronic illness. She has been able to achieve this in a supportive environment provided by her family. Kim monitors her symptoms, makes decisions about treatment options and balances her illness with attending school and other social activities. She does this with the guidance of her family and friends. She reports her chronic illness impacts on her ability to perform at school, travel, socialize with friends and participate fully in physical activity. She has strategies in place to be able to achieve these activities to the best of her potential. Living in rural South Australia impacts on her lifestyle. The implications of travel to and from the hospital (cost of petrol, wear and tear on the family car, demands placed on parents) and inability to be treated in her local area (lack of resources and trained health care professionals) are concerns for Kim. Kim and her mother Linda report a number of examples of how they have adapted to change. Primarily these relate to changes associated with Kim's age, such as increasing independence with management of her illness, continued stable health after initial belief that Kim was going to die, changes in family dynamics as the family members release some of the chronic illness management responsibilities to Kim, and embracing new treatment options. Both Kimberly and her mum are able to report benefits and positives associated with living with a chronic illness.

## Tom and Emily's story:

# Caring for a partner with Dementia

by Kristin, *Occupational Therapist, Mental Health Service, South Australia*

The subject, TOM, is a 90 year old male who experiences chronic obstructive pulmonary disease (COPD), skin cancer and dementia. He is married to Emily, 84, and they currently live in a nursing home where they have resided for 12 months. Tom was diagnosed with COPD approximately 12 years ago, resulting in shortness of breath, reduced fitness, and fluid on the lungs at times. He regularly attends appointments with a Pulmonologist. Tom has also had multiple skin cancers over the last 20 years, probably as a result of spending years out in the sun during World War II. He regularly attends appointments with an oncologist. He has had multiple skin cancer removals and skin grafts, often in succession when the first one has healed.

Tom also experiences dementia, which has been of gradual onset over the last few years. He currently remembers who his wife is, but has difficulty remembering the names of his children and grandchildren unless prompted. Tom was able to drive up until three years ago, although his wife had to give directions. Emily has never had a license. One of his sons currently has medical and financial guardianship, which Tom (in a limited capacity) and Emily supported. Emily also has a diagnosis of bone cancer and is being treated for pain only, due to the terminal nature of her illness. They moved from independent accommodation to the nursing home after this diagnosis was made. While in independent accommodation, they received domiciliary care nursing services twice a day to assist with bathing, dressing and mobilizing Tom, as for the 18 months prior he was unable to physically complete these tasks without collapsing due to shortness of breath, chest pain or low blood pressure.

Tom's personal experience of his illnesses was frustrating for him, as he had always worked outdoors and had played lots of sport, and had therefore been quite fit. There was some refusal on his part to change behaviours such as fixing things around the home that required physical effort, such as cleaning the gutters, and he would persist in walking long distances when a wheelchair was available. Tom's ability to change his behaviour was well supported by Emily, as she would encourage and insist on following the advice of doctors.

Emily is from a generation where there was perhaps less of a partnership between patient and health professional and where the patient was dictated to, so at times their children would attend doctors' appointments to ask questions, or about alternatives. Each of his health professionals were happy for and encouraged the family to be involved in the care and treatment, and especially the support of limiting physical activity.

When his dementia became more progressed, Tom was further frustrated, especially at onset when he was aware he was forgetting things. He was also reluctant to accept the domiciliary care service at first, until he realised that it would also help Emily. Tom's ability to self-manage his chronic illness reached a point where a true partnership between himself, his carer and health professionals was unable to occur. Due to the dementia at this time, he was no longer able to make decisions about his medical care, and the physical disability caused by both his chronic illnesses and his age curbed the behaviours that he had been advised against. In effect, his lifestyle choices were made for him by his wife and health care professionals. Tom was later determined by the Guardianship Board as unable to continue to make his own choices about his conditions and the treatment which he would receive for these. Obviously, a person's ability to self-manage is dependent upon their mental state and ability to make decisions, and total partnership and self-management is impossible or limited in cases where mental state is compromised to a certain level.

Tom's contact with health professionals was frequent appointments with a Pulmonologist, an Oncologist, and eventually daily contact with home care nurses, and then with doctors and nurses in the nursing home. Emily would accompany Tom to all appointments. As Tom had served in the war, his medical expenses were partially covered by the Department of Veterans Affairs. However, as he had not served overseas, he was only eligible for White (not Gold) DVA card, so the extent of the cover and services available was not as copious as it may have been.



## Tom and Emily's story

Tom was very reluctant at first to begin receiving home nursing care, but agreed when Emily injured her knee trying to help him get up from a chair. He adapted his lifestyle so that he was placed in a chair in the lounge room, after being showered each morning, and then assisted to go to bed each night. He used a urine bottle as he could not independently transport himself to the toilet. Emily and Tom were reliant at this time on others to transport them to appointments.

The impact of the chronic illnesses on Tom's life has been enormous. His lifestyle has progressed, both due to his age and his illness, from complete independence to almost total reliance on others. This has resulted in feelings of loss and grief, frustration, and anger.

The impact of Tom's chronic illness on his wife Emily, who is his primary carer, has been enormous also. Emily did not seek any medical treatment for approximately 15 years, as she was primarily concerned with Tom's health. She actively sought treatment such as the domiciliary care services, physiotherapy and occupational therapy for Tom and supported the lifestyle changes he was required to make. This eventually resulted in detriment to her own health and eventually both Tom and Emily having to move to the nursing home where they now reside. Emily discovered a lump on her breast about four years before they moved which grew and became a weeping sore. She managed this by wearing nursing pads, and it was only diagnosed as breast cancer when she had a fall and had to attend hospital where they gave her a full physical. Emily wanted to remain caring for Tom, and did not believe that she would be able to access appropriate support services to care for him in her absence, and so ignored serious symptoms of ill health to continue this care.

Through her admittance to hospital, Emily was able to access services to arrange a nursing home for both herself and Tom to stay together, (which she was unable to do from the community), as well as a range of palliative care services which provided for Tom as well as herself. Similarly, the domiciliary care service was accessed faster when Tom had a stay in hospital, rather than being referred by a community doctor. This raises practice implications for community health workers and GPs and, in part, demonstrates the currently reactive nature of the health care system as services seem to only occur in a timely manner during a crisis (i.e. hospital admission).

Some of the issues highlighted by Tom's case include community understanding of services available, ease of access, and opportunity to access (e.g. White versus Gold DVA cards). Chronic conditions have a huge impact on the use and cost of services, especially inpatient services, and the literature cites numerous examples of how working in partnership with individuals with chronic conditions is an effective way to reduce hospital admissions, reduce costs and result in better health outcomes for individuals.

Perhaps greater knowledge from Tom's specialist doctors, or his referring GP, about other services to support Emily and Tom may have deferred the outcome of loss of independence for Tom, instead of just treating Tom's symptoms. This treatment, although the doctors involved the family and patient in decision making, did not consist of a true partnership and self-management approach. Instead it constituted didactic practice such as just being given medication without real review of lifestyle or condition management behaviours. A more holistic approach from all health care professionals involved, including using a self-management approach would have resulted in improved health care outcomes for both Tom and Emily.

## Peter's story:

# When treatment causes more harm!

by John, *Physical Rehabilitation Counsellor, South Australia*

Managing chronic conditions comes down to people's outlook and any assistance necessary to gain positive outlooks, while appreciating one's weaknesses and working on one's strengths. It truly is the typical case for us all: Is the glass half empty or half full?

PETER was bitten 12 years ago by a mosquito in Victoria. Ten days following, all his joints were extremely painful. A blood test was conducted. Prednisolone was prescribed and the conclusion was that he had polymyalgia rheumatica. Medication caused a severe reaction, including shingles. Peter's hands became disfigured with rheumatoid arthritis (RA), followed by badly affected knees. He was told by a noted health professional that most likely the medication brought on the RA. The left knee was replaced some six years ago. Through the operation, Peter contracted Streptococcal A, resulting in him needing to use a walking stick and further medication. One year later the right knee had to be replaced. He remained on both Prednisolone and a walking stick. But then things got really interesting three years ago, as the Streptococcal A was taking its toll. He was given an ultimatum; either to have his left leg amputated above the knee or a poor chance of survival. The decision was made and so the leg was amputated. Unfortunately, the latter surgery caused two other infections to afflict him: golden staph (resistant) and pseudomonas, resulting in necrotizing fasciitis badly affecting leg musculature, heart failure, kidney failure, pneumonia and severe oedema.

Through the 1960s and 1970s, Peter was a prominent figure, heavily involved in and at the forefront of organic horticulture. He lectured all over the country and had been invited onto many radio segments. His wife (her second marriage) used to accompany him on many of his lectures, which included some community lectures amongst those delivered to prominent figures of science, politicians and farmers, as well as the general public. She also modelled for television shows. Furthermore, she assisted him in the writing of a manuscript on organic horticulture. These were very social people. He was nominated twice for an OAM and a (former) BHP Award for the Pursuit of Excellence.

Three years ago, life received a massive and sudden blow. By the time Peter exited a local hospital, he was on many daily medications, no longer able to lecture, suddenly unable to be the renowned personality at the forefront of organic horticulture, in a wheelchair and unable to care for himself personally. His wife had suddenly been thrust into the limelight as a primary carer. Social outings had abruptly stopped. Like two vastly opposite forces, life resembled little of its former colour.

Peter blames the hospital for the condition leading to his current state as this is where he contracted the infections and there would appear little consolation from the medical establishment. With regard to this matter, he chose not to take legal action. Yet he was strengthened with great personal determination, spurred on for the love of his family (wife, son and daughter). From the outset, he was determined to rise above the situation and 'make the most of what he had'. To this day, he awakes and praises God that he's alive.

Though both his wrists and shoulders are noticeably affected with RA, wrists in particular, and he frequently experiences pain in the neck, sometimes resulting in the consumption of a potent anti-inflammatory, and though he is confined (at the moment) to a wheelchair, Peter has one major goal: to stand. He has begun to finally engage in exercises to increase the strength and mobility mainly in his shoulders, right quadriceps and lower leg muscles. He engages in standing episodes to increase his ability in standing, determined to reach his goal. Follow up by me in his exercise regime has proved immensely important. Though Peter had exercises prescribed to him in the past, there was no follow-up and he lost interest. He sees his GP once a fortnight, and receives 24 visits throughout each week for personal care. He has great rapport with the care workers. With regards to his personal care, he said: 'I am a proud man, but I have to be realistic ...' Evacuation of his bowels has been a concern as to its unpredictability in the past, which has led to him remaining within the house when an option to go out was otherwise possible. Nonetheless, options have been investigated and there would seem to be some regularity emerging.

## Peter's story

Despite such disruptions, it would seem that both Peter and his wife's former social tendencies have ironically allowed for a relatively high degree of acceptance of necessary disruptions into their home life by others. His son lives home (in his mid-20s and attending university); father and son have a great reciprocating admiration for each other. His wife continues to run their local organic fertilizer business on a part-time basis, employing another person for the remainder of the time. She enjoys the social interaction out of the house. Their daughter, currently living interstate, has mentioned returning and helping to operate the business, which Peter intends to frequent in the warmer months and which he does currently visit from time to time. He "oversees" family gardening expeditions carried out by his wife and, in doing so, retains an additional link to his past field of expertise and passion.

Furthermore, Peter is contemplating having an autobiography written, which he'll dictate to her. This may reignite a past mutual involvement of togetherness and provide the opportunity for mental stimulation and a deserved indulgence in reminiscing. When asked of his friends, Peter commented that they had "the audacity to be dying" on him. Nonetheless, both he and his wife remain extremely active in going out. The use of cab-charges poses little concern and she enjoys the break in having to drive. I have been invited into the support services through my agency's In-Home Care service, adding to the health care professional team and care workers the ingredient of a physical rehabilitation consultant. The increase and motivation to exercise and the reasons behind such an endeavour have been established. A major contribution is given by Peter's wife, who now assists him in regular exercise and has become interested, once more, herself in excising. Peter's paramount goal of standing has also received a boost in the loan of a forearm walker. Rather than the right leg taking all his weight, which seems to be curtailing his attempts to stand, he can weight-bear to some extent through the arms. Why is this so important? (1) it is Peter's major goal, and (2) he has been told that if he can stand for two lots of 10 minutes, it would be possible to have a prosthetic applied to the left leg. Furthermore, a professor who knew of his case in the past has been invited into the team to add more assistance in this area, and is willing to be involved.

Several unfortunate and past situations experienced by Peter within health care he received weren't helpful to fostering a sense of self-management. He was told by a noted health professional, apparently, rather rudely from the inception of the idea of standing, some three years ago, that it was impossible; that he couldn't and wouldn't ever do it. Peter felt he was more a financial burden on the health care system; that he didn't rate as a human being who deserved such possibilities. Had he not had the social support of his family and, in particular, his wife and such determination, such a negative attitude from an 'authoritative' figure could have diametrically caused a major barrier in his self-management. Indeed, it would seem that it has made him more determined!

Though life was thrown into nasty disarray, these people met the challenges and, in doing so, many very positive options would seem to have been embraced whilst others await to be explored, including an increased interest in their business, which may be added to by the return of their daughter. Travelling may increase along with the sheer ability to stand. With continued social and service support, which has strengthened and become more proactive recently, Peter's goal would seem closer. With his determination, who knows what goals will well-up next? One thing I have noted upon my visits: these people have never lost that so very precious emotional expression: laughter and the ability to talk candidly.

## Clarice's story:

# The bitter taste of disadvantage

by Robyn, *Senior Occupational Therapist, South Australia*

**CLARICE** is a 27 year old married woman living with her husband, Hannibal and their dogs in public housing in an outer suburb of a metropolitan city. Clarice and Hannibal used to run a cleaning business but this failed, partly due to Clarice's ill health. They went bankrupt and now rely on an external agency to manage their finances. Their income consists of Clarice's disability pension and Hannibal's carer's pension. Clarice has a complex medical and psychiatric history. Clarice uses a manual wheelchair to mobilise, following an L2-L3 discectomy which was performed in an unsuccessful effort to relieve chronic back and leg pain. Prior to this Clarice walked, albeit painfully with crutches. Scheuermann's Disease of the spine can result in wedging of vertebrae but is generally not associated with severe spinal cord damage. Clarice also has hypertension, asthma and obesity. She now complains of numbness and weakness in her hands. Medical tests and investigations fail to adequately explain her symptoms and function. Clarice has had one kidney removed and a history of urinary tract infections. She now has severe urge incontinence and wears pads to manage this. She suffers constipation and occasional bowel accidents. She reports no sensation in her lower limbs and muscle testing reveals no active movement. She tires quickly on physical exertion and has limited aerobic fitness. Clarice has a history of bipolar illness and her medication is supervised by her husband due to a history of self harm. Clarice takes strong pain medication, drinks minimal alcohol and smokes cigarettes. She is waiting to see a Pain Management Specialist, Urologist and Spinal Injury Consultant and has been encouraged to re-establish psychiatric supervision. Clarice was accepted as a client by the community aged care and disability service earlier this year after a self-referral following discharge from a major teaching hospital. Clarice and Hannibal describe a steep learning curve since returning home in that they have had to adapt to her wheelchair dependence and further loss of function.

Reportedly Clarice was offered rehabilitation at the Spinal Injury Unit, but she rejected this because she understood it to mean permanent residential care. At that time she had limited understanding of how her lifestyle and needs were going to change and was disappointed that the surgery had not cured her of the chronic pain she had endured for seven years. Far from improving her situation, surgery appeared to her to have failed her, with resultant inability to stand and dependence on a secondhand wheelchair donated by the local Lions Club. Appropriate medical and psychiatric management and ongoing equipment funding and provision would appear to have been bypassed by inadequate discharge planning. Clarice and Hannibal speak defensively of their interaction with neurosurgical staff and appear unsatisfied with the information provided to them. Clarice was assessed at home by area team staff and referred to the pilot rehabilitation programme for three months intensive input aimed to maximise her level of function and reduce potential dependency on community support services. For the purposes of this analysis/ reflection, I have chosen to begin from this time in Clarice's life, when I met her as a staff member of the rehabilitation team. Clarice and Hannibal have divulged more details of Clarice's life experiences and these have been included to demonstrate their experiences, behaviours and interactions. Suffice to say that Clarice has alluded to an eventful childhood in which she was fostered after her father killed her mother! She has phone contact with her foster parents in Queensland and sees her sister who lives locally, but whom has significant social problems rendering her unable to assist Clarice. Another significant stress is the current court case involving Hannibal and a sister of Clarice, who is alleging sexual assault by him. This necessitates periodic trips interstate. Hannibal has several children from a previous relationship and has disclosed that he would be unable to pay accrued maintenance costs. Income is clearly limited, but the couple show generosity in their gifts to others and use opportunities to gain cash whenever possible, for example selling their seven Rottweiler puppies to the local pet shop and selling their computer skills and savvy as requested by neighbours.

## Clarice's story

One of Clarice's goals was to improve her ability to make meals and manage household tasks. Inspection of the pantry revealed no ingredients, just a range of instant foods such as coffee, weetbix, pasta and instant noodles. There were no fruit and vegetables. Hannibal stated, "We have lost the art of shopping". The social determinants of health, poverty, depression and poor education are clear. I wonder whether Clarice and Hannibal realised that a holistic look at their lifestyle, coping mechanisms and strategies was needed, rather than or in conjunction with appropriate health care management. They often speak of their disappointment in the medical and societal systems that have failed them, but do not verbalise their contribution to the process of change to navigate these complex systems. However, Clarice complies with all efforts to reach her goals and is beginning to accept that the problem solving process and readiness to change are required. It is easier to discuss these issues with Clarice when we are working together on a practical task as her capacities, both strengths and weaknesses, are most transparent in the doing, not the talking.

Clarice's wheelchair dimensions preclude access to her current bathroom and toilet as the doorways are too narrow. The public housing authority has the couple listed as a "Priority 1" for relocation to more suitable accommodation as home modifications have been deemed too expensive in a house that will be sold off due to structural problems. Consequently Clarice has to use a commode to go to the toilet. Given her urological history, this poses a high infection risk. Inability to empty the commode bucket, combined with urge incontinence promote unsafe, rushed transfers and poor hygiene. Similarly, Clarice has to transfer onto a mobile shower chair outside of the bathroom as the wheelchair cannot fit through the door. As a generic service, the community aged care and disability service does not have the sort of specialised bariatric equipment Clarice needs, now and in the future.

The rehabilitation staff have written a letter to public housing authority on Clarice's behalf, supporting her priority needs for transfer and pointing out the health issues at stake. It is disappointing that there is not further dialogue between the government agencies involved to achieve a holistic and efficient outcome for this couple. They tell their history to many agencies and seem to slip between the cracks when it comes to an agency willing to assist them in coordinating these issues. Added to the physical access issues, local pavements are in poor condition, making outdoor wheelchair mobility less enticing. Neighbourhood disputes are common conversation topics. The local shopping centre is almost derelict as facilities have not been upgraded to compete with city centre malls.

However, a trip to the local community food cooperative did prove useful in demonstrating a source of low cost, nutritious food packs which can make simple meals. Clarice was motivated to buy and try these meals and returned to purchase further meal packs herself. Whilst working with Clarice, I noted her sense of alienation and she spoke of repeated difficulties in interacting with people due to perceived discrimination, on the basis of her appearance including obesity, wheelchair dependence and poor quality clothing. Clarice and Hannibal both believe that doctors treat them poorly once they become aware of Clarice's mental health history and that the general public treat them poorly due to their appearance and lack of money. The absence of clear differential medical diagnoses appears to be interpreted as functional or conversion reactions with associated lack of willingness to be involved.

An example of this occurred when the couple took a short tourist holiday, funded by Clarice's parents. The couple were not satisfied with the cleanliness or the 'disabled facilities', including lack of a ramp for access and inadequate hand rails. Somehow the confrontation must have escalated because the police were called and I was shown an explosive letter from the Hotel Manager, banning them from any future stays and threatening to sue them if they "defamed" the establishment any further. It also accused them of not having any money, as they did not use the dining room. Hannibal stated that he would seek legal advice to reply. Clearly there are communication difficulties for this situation to have become so antagonistic. Negotiation and problem-solving skills are called into question.

Another example was when the couple decided to purchase an electric wheelchair for Clarice to mobilise in from a private company. Given that they knew very little about wheelchairs I recommended that they trial it at home to check its suitability before purchase. An electric wheelchair would not have been available from the community aged care and disability service. I explained to the couple that the wheelchair on trial was too small, both in seat size, weight capacity and for comfortable seating position. Despite these shortcomings the couple decided to purchase the chair anyway, only to find their application blocked when the company deemed their financial status too uncertain to guarantee regular payments. Clarice and Hannibal angrily reported two more instances of shop staff turning them away, despite the cash they had. Eventually they purchased a lightweight manual chair from a company that “treated us like people”, and upgraded this to the correct weight tolerance chair at my suggestion. They found that my saying they wished to exchange on recommendation from a professional person helped them to get instant service.

Telephone conversations with Clarice's new GP, whom she had selected because he himself had had experience of chronic illness and was seen by the couple to be more receptive to them, revealed that Clarice has changed GPs frequently and that there were many issues to deal with, with many specialists and a clear need for all the people involved to be working together. At the next rehabilitation meeting staff raised the need for clarity of goals, given the multiple and complex needs arising. Clarice and Hannibal's current presentation is the accumulation of lifestyle patterns and events over many years. Clarice has, in my view, been “victim blamed” by systems and organisations that have failed to engage her effectively in determining and overcoming her health problems. The process and channels for referral to the Spinal Injury Unit were investigated and from this come the involvement of a representative of the Para-Quad Association who after several visits and discussions with us, began to advocate on the couple's behalf. This person has organised consults, brought urgent matters forward, accompanied them to outpatient consults and collated reports from all sources in an effort to bring Clarice to the correct pathway for services that will support her long term.

Working with Clarice has been challenging. She can become frustrated with tasks and has poor impulse control, needing support to consider options before making untimely decisions. She is easily distracted by pain or by the enormity of her complex problems, but remains strongly focussed and motivated to do things for herself and with a great sense of humour. Her stated goals are being pursued by practical activities, with emphasis on physical and psychological strength and control.

For Hannibal, the role of carer may be all consuming; he has spoken of the need for some time for himself. Clarice has become used to relying on him for assistance. Hannibal uses drugs and alcohol as stress relievers. Whilst he reports that he has the capacity to handle contingencies, I have observed a raw survival instinct rather than strong or resilient coping strategies. He and Clarice both talk the talk, but walking the walk is much tougher.

In summary, there has been a whole line up of staff involved with assisting this client and her husband. This essay has reviewed only the most recent time period in an effort to analyse and reflect on how one person has navigated an extremely complex system of care with a poorly understood set of problems and under-developed self-management skills. My relationship with Clarice and Hannibal has been as much about professional expertise in rehabilitation as it has been in encouraging them to resume control and responsibility for their lives and providing some directions for their map reading skills of the health system and community they live in.

## Michael's story:

# Mental health recovery – the art of listening

by Patricia, *Mental Health Nurse, South Australia*

MICHAEL has been a resident of the psychiatric hospital for the past four years. He is 24 years old and has a diagnosis of Schizophrenia. When first admitted to hospital he remained in his room, wore a beanie pulled down over his eyes and head phones that played music so loudly that others could hear it. He ate all meals in his room as he was so disabled by his psychotic symptoms that he was fearful of all the other patients.

His parents were devoted to him. Michael's father had been a teacher who suffered with depression and had been given a diagnosis of Bipolar Affective Disorder in his late twenties. His father no longer works. He lives in a unit which he previously shared with Michael. Michael had been aggressive toward his father and other residents in the group of units. Michael also damaged the unit and the pair were at risk of losing the unit with the owner tired of the repairs required. His father felt more and more depressed by Michael's behaviour. Michael had been cared for by his father following some inappropriate behaviour with his sister, which resulted in mother and father separating. His illness has had a catastrophic impact on the family.

Michael spent the first year of his time at the hospital in his room, at the insistence of the family who visited every day, delivered food and replaced the batteries in his headset. For whatever reason, the staff had not challenged this behaviour and allowed this young man to stay in his room watching TV and excluding himself from all that was happening about him. He was transferred to a rehabilitation ward after 13 months on another ward. These patterns of behaviour were well established and challenging them was very difficult. It was here that I met Michael and his parents and they were introduced to Individual Program Planning (IPP) meetings that have continued since then. The first meeting was spent acknowledging their disgust at the system that had incarcerated their son, and the system's failure to assist them over the past five years.

From there began a long progression back to society. By using a model of social inclusion we began taking Michael on short outings to coffee shops at times we knew not many people were around. We started exploring his goals and over the next 18 months progressed him to social interactions with others to shopping at the markets some distance away. We encouraged his parents to take time out for themselves and actively engage with Michael.

After four months from arrival on the rehab ward, Michael's parents went on an overseas holiday together. This presented a wonderful opportunity for staff, as Michael's parents had continued their daily visiting with Michael often occupying him for eight hours a day. Little could dissuade them from this attention to his needs. During the parents' absence, staff were able to engage with Michael on a one-on-one basis. This began a turning point for Michael where he began to believe in his ability to take control of his life. We found that he was able to make decisions for himself. He now describes this time as realising that we wanted to help him back to the community. Up until this time he stated that he felt his family knew best and that we were not to be trusted. He stated that he feared us because he thought that we wanted him to stay in hospital forever. He said that he coped with this by not thinking about the future and looking forward to his parents visiting. In these few weeks Michael made a huge improvement in making decisions. Through the decisions he needed to make he began to feel empowered and staff started talking to him about the future. What did he think the future looked like? How would he like to change it? What would he like to do? What did he think was limiting him from attaining what he wanted? It was at this point that we also had the opportunity to discuss Michael's anxiety levels and how he could control them. He now describes that he became more motivated to discuss the symptoms of his illness and the feelings of anxiety that kept him in his room. Once he was able to discuss these feelings he was able to also discuss controlling these symptoms.

When Michael's parents arrived back from their holiday we were able to assist Michael to present how he viewed his world at the IPP meetings. These meetings progressed fortnightly and it was here that we were also able to discuss his parents' fears. It has been a very long process and one that I acknowledge was brought about by failing to empower Michael regarding choice in the first place.

Some months back Michael was introduced to the Flinders model. He was a wary participant however after several sessions warmed to the process and enjoyed filling out the Partners in Health Scale and discussing the issues with the Cue and Response interview. With each session we revealed more and more of the 'onion leaves' until recently he was able to discuss in a frank and open way his belief that until now no one had listened to him. Even in the IPP meetings he felt that everyone had their own view of him and didn't really listen to him.

He described having an NGO worker who would take him out but who talked at him and problem-solved for him and he felt overwhelmed by her and unable to stop her from progressing things without his consent. She had a belief that he needed to live on his own and went out and bought a washing machine and refrigerator without taking him with her. Negotiations were made with the Public Trustee without his knowledge and he was expected to be happy about it. He felt confused, angry and hurt but didn't tell anyone because he thought it would cause too much trouble. He stated that they were big purchases for him and he would have enjoyed making the choice. He felt robbed of the experience. He often felt he was not worthy of enjoyable experiences and perhaps this was why he was denied them. He described these feelings in such overwhelming terms that I felt moved to tears at the lack of compassion that had been shown to him during his long stay in hospital. It was his experience of the hustle and bustle that goes on all around him each day that he had become a nothing in this place. People looked at him but they didn't see the real him, who thinks deeply and feels the hurt and the pain of losing an identity in an institution.

Michael and I discussed ways that he could claim his identity back. He asked for a new NGO worker; one that wasn't overpowering and one that would have a conversation with him not just talk at him. He asked that if this worker didn't work out that he could try another until the relationship was right. He asked that the staff not make decisions for him. He wanted to start making his own decisions. He wanted to decide where the NGO worker took him, what they would look at and how best he could use the time given to him. He wanted help researching things at the Library and he also wanted some assistance with his Christmas list for the family. He knew what he wanted to buy but he didn't know the best places to go shopping because he hadn't been shopping for so long. He no longer wanted to go out for coffee and then wander aimlessly. He wanted to plan his outings and have his own goals. The transformation that was seen in Michael was quite remarkable. It was obvious that he had not been given a similar opportunity to take some control for a very long time. The Flinders model gave to him whilst other strategies had continually taken from him.

Michael has been progressing rapidly over the past month. He has bonded well with the new NGO worker and Michael has set the date that he will move permanently to his unit. He is currently spending three days a week there and is enjoying it immensely. He has been linked to community programs that will break for a short time over the holidays but his NGO worker has arranged for extra hours to be made available to Michael during that time if he would like to go on an outing. Once Michael has moved into his unit he will start a part-time job, five hours per week in a fruit and vegetable shop that is within walking distance from his home. He will be assisting to put the fruit into the cool room, wipe down the benches and sweep the floor. He has been doing this for one hour on one of the days he is currently at home and enjoys the interaction with the other workers and customers who have welcomed him.



## Rosalie's story:

# A self-management compass to guide you

by Lyn, *Community Health Nurse, South Australia*

**ROSALIE** is a 50 year old white Australian woman, a mother of two adult children. Her daughter, who is in her 20s, is currently living at home, managing depression, and studying at a TAFE College. Her son is married and living interstate, with his partner and very new baby. Rosalie would love to visit her son and first grandchild. Rosalie is unemployed, was diagnosed and treated for breast cancer four years ago and is currently being managed by her GP for diabetes and depression.

Rosalie lives in public housing accommodation and relies on buses and walking for transport. She is not a confident woman; she has a laugh that appears to come from nervousness, and although she conveys understanding, participates in and follows conversations in the moment, on follow-up meetings we mostly repeat and go over previously discussed information. Rosalie has very few friends, keeps a very clean and tidy house, and in fact prefers to cancel social appointments or opportunities to go walking so that she can tend to her housework. The father of Rosalie's children was violent and left her to raise the children alone when they were very young. There has been no contact with him since then. Rosalie is very creative and enjoys doing arts and craft, although the cost can be prohibitive.

Rosalie is on Tamoxifen which apparently interacts negatively with her diabetes management; she monitors her glucose, is insulin dependant and visits her GP every three months or when necessary. Rosalie has reasonable knowledge of her medical condition and treatment. She believes she is overweight and often feels tired and has many restless and sleepless nights. Rosalie has very little memory of ever feeling well. She says that she feels she has been struggling to "stay a float" in her life for a long time and mostly feels responsible: "I married the wrong man, didn't stay at school ... Never had a good job (because she couldn't get one) and ... everyone has their own problems, especially my family ... and sometimes I just can't be bothered and will eat that extra biscuit or cake."

Rosalie spends a lot of time finding out about things she can do differently and mainly how she can get into a great routine with walking regularly eating well and managing her health. Caring and supporting her daughter can sometimes take her attention away from her program of looking after herself. In fact, Rosalie and her daughter are at different times carers of each other. Rosalie talks about looking after herself in terms of it always being a major effort, something that has never been an easy part of her life and is therefore more like a challenge. In contradiction to feeling mostly responsible for her state of well being, Rosalie also views her ill health as something that is beyond her control, predetermined and genetically imposed requiring intervention from the outside.

Rosalie has always managed alone and with the assistance of her daughter, she has knowledge of what is available for support and assistance in the community but tends not to pursue it because she believes others are in greater need than her. She has always made herself available to her sister, who also had breast cancer, particularly in the area of housework and shopping. Rosalie cannot pass through your service and remain unnoticed, but she can pass without being effectively 'served'. She is very resourceful and keeps informed through public notice boards, organisations' newsletters and the local newspaper about groups and activities. She can and does attend the same group over and over again.

I first met Rosalie 12 years ago, pre diabetes and breast cancer, in a domestic violence support group that I was facilitating. Some years later I met her again at a 'women talking and walking together' group I was again facilitating. Rosalie this year registered and attended a group for 'Women living well with a chronic condition' that I was running. She attended every session and would often take the conversation into a very personal experience that was not directly or remotely connected to the issue at hand. At the end of the course I asked Rosalie if she was interested in a 1:1 consultation to work with me on developing a self-management care plan using the Flinders model.

Although we had discussed the principles of self-management, problem-solving, goal setting and care plans in the group, I again explained what they were, why I had asked her if she would be interested and what she could possibly expect from the process.

Working with Rosalie has highlighted many issues for me as a health care worker. We as workers need time and flexibility to explore and become familiar with the individual's environments, because that is what informs their level of understanding, knowledge, experience and access to services or opportunities that support their capacity to achieve health and well being. It is only then that we can truly partner a client in a journey of recovery. I'm looking forward to discovering the source of Rosalie's resilience and resourcefulness as we continue to work together. As well as time and flexibility, a mixture of services in the community (including approaches and issues being addressed) are required to meet the diversity of needs in our communities. Services may exist, but access and engagement of clients requires the application of primary health care principles and resources. As service providers, we need 'tools', protocols and evidence based practices. We also need to be supported by the structure and processes in place at the service/agency level. The use of the Flinders tool with Rosalie has been a great opportunity to get an extensive, holistic picture and assessment of her current situation. With this we could then prioritise and plan ways to meet her goals.

Mostly in this story, I'm grateful to have reconnected with Rosalie at this time, where my knowledge and experience of working with people, particularly women who live their life with a complexity of experiences (physical, emotional, mental, social and economic), is a supported part of my work.

## Cecile's story:

# Resilience Personified

by Grenville, *Non-Government Psychiatric Disability Rehabilitation and Support Service, South Australia*

CECILE has a diagnosis of a Borderline Personality Disorder. Some of the issues Cecile struggles with are anxiety, compulsive behaviours, hoarding, untidy living conditions and self-harming. One common set of descriptive clusters commonly named as Borderline Personality Disorder include:

- Attachment issues: cycles of rejection and abandonment
- Fragile self and emotional dysregulation
- Self-harm and suicidality, crisis-proneness and self blame
- Dependencies and addictiveness
- Black and white thinking
- Mega-stress situations

(Hartstone, 2006, unpublished CBT workshop handout notes)

Borderline Personality Disorder is such a difficult to understand and counter intuitive description, particularly for this person. A much better way to view Cecile's condition is to see her as a survivor of trauma. During her childhood and through into adult life Cecile's father was abusive toward her, her mother had depression and it is possible she was neglected as a child because of her parents' learning difficulties. She has been in foster care, in youth accommodation, been detained in psychiatric institutions and has had periods in boarding houses. Some of the challenges she has faced are depression, hypothyroidism, financial strain and multiple family problems. Because of the hypothyroidism, there is added complexity of co-morbidity relating to that condition and of Cecile's tendency to overdose on the Thyroxine, prescribed to stabilize that condition. Consequently it is sometimes difficult to understand what is going on in her life. Cecile is a survivor; she has had part-time jobs, performed consumer consultancy roles and been a volunteer support worker. She now lives independently although she finds it a challenge to manage her home. Cecile is supported by a tenancy support program but she has found it difficult to actively engage in this process. Some of the challenges with housekeeping may stem from issues with her anxiety. Cecile is very observant and attentive to her surroundings, as are many survivors of ongoing trauma, where vigilance was central to trying to find safety.

### Personal experience of chronic illness

Cecile's journey has been a life of interfacing with child and adolescent mental health services and adult mental health services, hospitals and their emergency departments (ED). Often in these settings Cecile feels that she loses her voice and is not listened too. She wrestles with ways to find her voice and be able to express her views, which in her past were ignored or overridden. As an "unemployed" person on a Disability Support Pension (DSP), I have observed that on occasions she is not treated with the respect and care that she deserves. This seems to me a social equity issue and reflects a misunderstanding people have in their dealing with her. That is, they do not understand that Cecile is a survivor of trauma, and possibly neglect. In this context she has done well to survive and she would like greater recognition of the good things in her journey.

### Ability to change her behaviour

Cecile has progressed from institutionalisation and supported accommodation to independent living. She has recently had a job assessment and is looking for ways to find employment and meaningful daytime activities. In her role as a volunteer support worker she has helped people get out of their homes and make connections in the community. Over the last two years Cecile has gone from 100kg to 72kg and she is very proud of this achievement and being able to find more attractive ways to present herself. While she feels her medical conditions have not been clearly explained to her she is moving toward a better understanding of herself.

### Cecile's interaction with support services

Cecile seems to have a fraught relationship with adult mental health services, possibly based on non-consensual treatment, such as being detained and experiencing non-voluntary Community Treatment Orders. Conversely Cecile would like a more attentive level of service and this reflects some of the contradictions of her past experiences as a child, of wanting to be loved (cared for) and being mistreated by those whose responsibility it was to love and care for her. So that at times the inappropriate and non-honouring responses of her childhood are revisited on her, partly because she is still learning how to relate to people in the most effective way.

Cecile has been supported by non-government organisations (NGOs) providing psychosocial support over the last 15 years and says that this has been a source of non-judgemental support for her, most of the time. Cecile's most challenging relationships are in the acute hospital settings.

I have attended several meetings set to review her management plan, within adult mental health and hospital ED settings. Cecile has not been happy with these plans. One of the requests Cecile made in respect to the plans was that they acknowledge her journey of recovery and improvement. Cecile would like the plans to include historical data regarding ED admissions and crisis phone contact which Cecile believes have reduced over time. It is difficult to understand why this simple request that would mean a lot to Cecile has not been able to be facilitated.

The most appropriate evidence based treatment for Cecile is probably Dialectic Behaviour Therapy (DBT), or therapies that seek to help her with emotional regulation, self-soothing and problem solving. At this stage this DBT treatment is not available for Cecile. This is probably another example of social inequity, where appropriate treatment is not possible because of where she lives and lack of financial resources. However in the most recent care plan there is evidence of Cecile continuing to be a resourceful survivor. She is getting psychological therapy which is addressing various aspects of her life. In the most recent care plan it was agreed that one of the Community Support Workers (CSWs) who has a nursing background will attend a medical specialist appointment with the client to help the client ask questions and process information. A greater knowledge of her conditions will be an enabling process for self-management.

### Implications for carers and other supports

Cecile does not have a carer as such, but she has a number of friends who over the years have provided Cecile with consistent care and respect. In some ways Cecile may not have always been able to respond with the measure and evenness she would have chosen, however these connections are still there. The effects of abuse and neglect provide special challenges to carers and supports because responses from the person cared for are sometimes not as measured and controlled as might be from someone without their experiences. This is because typically people with such pasts have experienced their personal realities not being confirmed by those around them and therefore they may be inclined, perhaps in desperation or panic to react strongly to emphasise their experience, and find that strong displays of emotion get noticed/reinforced in ways that more modulated ones do not. Hence this sets up a repeating pattern and little chance to learn more adaptive ways to deal with personal distress and solve problems. Linehan (1993) points out that people who develop Borderline Personality Disorder are characterised by very high sensitivity and very intense responses to emotional stimuli and "a slow return to emotional baseline once arousal has occurred" (p2). She notes that this makes it more difficult to learn ways to modulate the strong emotions, especially without support from others in one's family or social environment. She argues that repeated experiences of invalidation by one's environment is the second most significant factor in producing the development of a Borderline Personality profile (Linehan, 1993). Hence it is not surprising that she also observes that "more so than most, borderline individuals seem to do well when in stable, positive relationships and to do poorly when not in stable relationships" (p7). Cecile's ongoing friendships and relatively consistent experience with NGO support can therefore be seen as centrally important in assisting her journey of recovery and experience of herself as a person of worth.

In respect to mental and physical health services for Cecile there remain lots of opportunities for greater collaboration. As a support worker, I sometimes feel like Cecile, that I am not being listened to either. This may be because of limited resources, a lack of energy, poor training and management processes within adult mental health service, or simple prejudice towards non-clinical workers.

## Cecile's story

Cecile's current care plan has identified the following tasks to be focused on:

- Increasing her knowledge of conditions and medications.
- Improving her input into decisions regarding her treatment.
- Keeping a diary that charts food, emotions and energy levels.

Her Goal Statement is: "In six months I'd like to be connected with disability job network services." Such a goal shows her focus on continuing to progress in her life and to understand and manage her difficulties and treatment better.

### Practice implications for the worker and agency

Survivors of trauma present high levels of complexity and chronicity. The present challenge is to achieve greater collaboration between her various treatment teams and to assist Cecile in continuing to move forward in the way she wants to go. Over time both Cecile and workers have been and will be discouraged when agreed tasks and agreements do not work out and have to be revisited many times. However Cecile is a client for whom I can see such good potential in the future and enormous opportunities for her journey, based on the progress she has made so far, and it is important that hope for the future and belief in her ability is maintained. She is able to seek educational opportunities along with paid work, and moving off the DSP. In respect to the challenges of keeping house there are many resources available to support her when she is ready to tackle this in small steps. Cecile is a survivor of experiences most of us would have no personal knowledge of. She has the rest of her life to keep building on ways to manage her condition, and to make contributions for herself and others.

### References

Linehan M. (1993) *Skills Training Manual for Treating Borderline Personality Disorder*. USA: Guildford Press.

### Notes for CCMS support people:

#### STRENGTHS

Cecile is well aware of how health systems work. Cecile has a strong sense of right and wrong due to her black/white thinking and emotion driven concept of life. Cecile is very loyal and values feeling needed.

#### BARRIERS

Cecile uses many 'survival' techniques to get her needs met. She has many 'skills' which unfortunately get misinterpreted negatively as personality disordered help-seeking behaviours. She is often judged negatively as a nuisance to health services and as a manipulator.

Trust is central to how Cecile interprets her interactions with others. She will be very quick at picking up their negative judgements and she will openly respond with like views about them. Any therapeutic relationship will disintegrate rapidly under these circumstances.

#### OPPORTUNITIES

Respect and listen.

Acknowledging the journey Cecile and taken and her achievements in managing to get her needs met from services will have a positive impact on her self-esteem.

Services could use much of Cecile's ingenuity and channel her energy into positive pursuits. Give her a role and purpose. Value her contribution and opinions.

Support workers will play an important role in helping Cecile navigate health and welfare systems, problem-solve and interact with staff to ensure that they listen to and respect Cecile. This will likely prevent unhelpful displays of help seeking that will be misinterpreted negatively by them and allow them to see Cecile in a more positive light. It will also build more constructive role modelling for Cecile to follow.

#### IMPLICATIONS FOR CCSM SUPPORT

Cecile will thrive of positive feedback and others expressing pride in her achievements.

Consistent and coordinated approaches to support and care will be important to Cecile as will consistency of staff that she trusts and who relate to her in a clear consistent manner. This will ensure clear communication of Cecile's needs and how health professionals can engage her positively.

Have a plan and stick with it. Fully involve Cecile in its development. Openly acknowledge the unhelpful styles of interaction and ask her what would help prevent this. Include her in responsibility for finding solutions and share the planning of this openly with her.

Practice tolerance and patience. This will be a long journey of unlearning some styles of interaction for Cecile.

## Jean's story:

# The Clock Ticks ...

by Justine, *Dietitian, South Australia*

**JEAN** is an 84 year old retired school teacher who lives in her own home with her pet dog. She has several chronic conditions including asthma, osteoarthritis of hands, shoulders and elbows and arthritis through knee joints. Jean was also diagnosed in 1994 with an oesophageal pouch (Zenker's Pouch), which did not give her much trouble until recently, when she was hospitalized for aspiration pneumonia. Jean requires help with shopping, cleaning and uses her walker to mobilize both indoors and outdoors, as she is unsteady on her feet. She also uses her walker as her chair within the house, rather than 'normal' chairs, which she finds difficult to sit on. Since her discharge from hospital, Jean has had to make further adjustments to her diet and lifestyle in order to accommodate for her swallowing problems. She requires food of a liquid consistency as solid food gets caught in the pouch. Jean takes several medications, most being complementary therapies and unavailable on the pharmaceutical benefits scheme. These also include therapies of proven benefit, such as glucosamine and calcium tablets. In addition to medications, Jean needs to supplement her diet with Sustagen drinks, to regain weight lost during hospitalization.

Jean gets very frustrated by her body weakness and lack of dexterity which affect her ability to finish or even start small tasks. She describes frustration around loss of full independence which makes planning for day to day activities at times futile. For Jean, even decisions about simple tasks that people take for granted such as 'how to get somewhere, what tasks to do, when and how much time to spend on tasks' is often overwhelming. This perceived loss of control over task management is an important issue for Jean. A large proportion of her time and energy is taken up by 'articulation work' (Corbin, 1988): organizing, coordinating and carrying out even trivial tasks, leaving little time for general relaxation.

She also finds keeping to her medication schedule and her daily routine of meals and medications challenging. Meal planning and food preparation can be quite a task, even for people who are healthy. But for Jean, every step around food is a chore: having to decide on what to eat, based on the limited choice of foods she can manage. Making sure that the food is available as last minute shopping is not an option.

This applies also to having to prepare the food and finally being able to swallow her food safely, let alone enjoy it! Furthermore, each step of the process takes extra time due to her loss of dexterity. It is therefore quite easy to appreciate the amount of work that Jean has to carry out just to get correct nourishment!

Keeping to a strict timely routine and being organized to take regular meals and medications are essential aspects of Jean's self management tasks. Any small diversions can cause major disruptions to her strict routine. Time is precious to Jean as any "loss of time can be very difficult to recover" and throw her out of balance. Jean also perceives that her time is controlled by others with precious time being lost through phone calls, private or unsolicited, unexpected visitors and expected visitors who arrive late. When time is lost "Something has to go and it is usually your body routines".

Health-related appointments are also often difficult to fit into the daily routine, not only because of medication schedules, but also issues around transport and timing of appointments. Unreliable transport and delays in appointment can also cause delay or missing of meals. They can also incur additional costs, for example when taxis turn up late and having to pay a fine because the appointment cannot be kept.

## Jean's story

Jean's social life is very restricted due to amount of time required for her self-management tasks and lack of transport. Jean has to attend regular medical appointments and uses taxis for her medical appointments, which can be costly when the fare is not covered. Jean enjoys playing scrabble and attends a monthly meeting at a local community aged care service. She also likes to spend time with her son and his family. However, lately she has become increasingly isolated, being too unwell to participate in her usual activities. Her social outings are also limited to day outings due to lack of transport.

Despite these challenges, Jean is very capable and motivated to self-manage and continue living a meaningful life. She has modified her diet to maintain her nutrition and safe swallowing and is very diligent about eating properly to maintain her strength. Jean has learnt ways to manage her daily work and accommodate to her chronic conditions, but has had to accept a lower standard of house cleanliness and support from others. She receives support from various health professionals from the community aged care service, including her service coordinator, Dietitian, Speech Pathologist and also has help in her house for cleaning. She has been provided with a range of equipment to facilitate daily activities. Jean describes that her need to maintain some sort of control and independence over her life helps her manage.

Jean is someone I would describe as a very resilient person and I would like to reflect further factors which contribute to her self-management capacity. From a health provider aspect, the approach to her care appears to have been holistic and based on collaborative decision-making. Her doctor also demonstrates a holistic approach to her care. He weighs her regularly and encourages her to take her Sustagen drinks and other supportive therapies to maintain health. Medical professionals who have been involved in Jean's care have provided her with information about her medical conditions and copies of their correspondence to other medical professionals.

There are also many intrinsic factors which contribute to Jean's resiliency and self-management ability. These intrinsic factors have been shaped by Jean's early life experiences. Jean came from a poor social background and was brought up during the Depression years. She reports never being close to the parents, her mother being very strict and her father disinterested. Jean was always a bright child and used every opportunity to expand her mind through creative thoughts and images. In some instances where she was locked in her dark bedroom for punishment, her escape was to think and retreat into a world of her own. As she was not allowed to bring children home, she would also often play outside on her own and create imaginary people to whom she would talk. Jean's use of imagination and play activities to find refuge from her home situation helped her cope with her life situation. Positive interactions with significant people in her life also helped her develop resiliency. Her Grade 7 teacher, for example, gave her support and encouragement and helped foster her strong self-efficacy. She once told her mother that Jean was like a cork: "The harder you hold it down and the higher it pops up". At times in her life, Jean would remember this and say to herself, "things are hard but they will get better". Jean's innate resiliency was also further developed through other interactions with her environment (Deveson, 2003). Indeed, hardship in those days was something that one expected and learnt to deal with. Jean became used to hard work right from an early age, having to look after her sick mother and doing chores around the house, in addition to going to school.

Societal beliefs and policies of the time around education have also contributed to Jean's self-management potential. Jean completed her primary schooling with very high grades which enabled her to attend high school, against her mother's wishes. She was forced to leave high school at the age of 14, but eventually obtained a scholarship for a business college where she learnt office skills. Jean's social and economic circumstances have been shaped by the policies of the time. She was fortunate that policies of the time supported her to have a career as, had it not been for the scholarship, she might have remained at a low educational status, which may have hindered her self-management potential.

Jean has also had exposure to chronic illness and has learnt many life skills over the years to accommodate to chronic illness, through her experiences with her sick mother, but also through her own ill-health. Jean had to give up work as she developed tuberculosis at eighteen and half years of age.

Although Jean has a lot of inner resources that she can draw upon to help her self-manage, there are many implications from a service provision aspect that need to be considered to provide appropriate self-management support. For Jean, having control of time is essential to maintain a sense of independence and control over her life. It is therefore important for health providers to keep this in mind when phoning or making home visits.

Health professionals also need to consider how their recommendations impact on her time management. It is also important to consider Jean's emotional health as Jean is not used to expressing emotions, coming from a family where expressing emotions was a sign of weakness. At this stage, Jean is managing her emotional health as she is still able to maintain a sense of control over her life.

However, as Jean experiences further loss of independence, managing her emotional health could become an issue for her. Interactions with health professional therefore need to be holistic by considering not only her physical needs but also her emotional needs.

### References

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## NOTES



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