

## Coronary artery bypass graft surgery: discharge planning for successful recovery

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**Background.** Coronary artery bypass graft (CABG) surgery is a lifesaving intervention, but the early recovery period presents a number of challenges for patients, carers and nurses. Early and adequate discharge planning based on in-depth knowledge of the post discharge experience can help to ensure optimal recovery.

**Aim.** This paper reports a study to examine the range of postdischarge issues, concerns and needs of patients and their family carers after discharge after CABG surgery, and explore their perceptions of unmet needs 1 year later.

**Methods.** A two-phase naturalistic inquiry was undertaken. Interviews were conducted with 30 patients and their carers 45 weeks after coronary artery bypass grafting (phase 1) and 1 year after the initial interview (phase 2). Thematic analysis was used to identify the major concerns of participants.

**Findings.** Almost half the patients experienced heart surgery as a huge personal shock. Adjusting to life afterwards was difficult, and they experienced a variety of changes, including pain. An unexpected finding was a heightened sense of body awareness and the need for postoperative physical adjustments. The financial implications of surgery were a major burden. Lifestyle adjustments were important and led to suggestions for support services, using telephone support and/or community patient networks. All participants recommended strengthening discharge planning with more accurate information about what to expect during recovery, to help them anticipate fluctuations in health and wellbeing. Carers experienced a wide range of unanticipated feelings during early recovery and had to deal with a number of personal changes.

**Conclusions.** The findings suggest a need to improve discharge preparation and provide enhanced home support services. Further research should evaluate models of periodic follow-up and mechanisms for mutual support, and compare the experiences of cardiac patients and their carers with those of other surgical cohorts.

### What is already known about this topic

The numbers of surgical interventions for cardiac disease will continue to increase, given the effectiveness of surgery in reducing mortality.

Discharge plans addressing the early recovery phase after coronary artery bypass graft surgery have thus far overlooked a broad range of longer-term patient needs.

Little attention has been to the self-defined needs of carers of these patients.

### **What this paper adds**

Patients' and carers' needs for information and support following coronary artery bypass graft surgery are not being met.

Patients' and carers' would like more professional support and follow-up after discharge.

Heightened body awareness and adjustment to postoperative physical changes are important issues in this client group.

### **Introduction**

With patients discharged home 'quicker and sicker' than in the past, the immediate post discharge period is of concern to nurses attempting to provide continuity of care between hospital and home, and to family caregivers, who typically give assistance for longer periods than in the past. Continuous and appropriate care will continue to be important for those caring for cardiac surgical patients, given the prevalence and success of cardiac surgery in countering the leading cause of death in Australia and elsewhere (Australian Institute of Health and Welfare 2001, 2002, World Health Organization 2003).

For nurses, lengthened periods of home and community care require timely, appropriate and evidence-based discharge planning. For coronary artery bypass graft (CABG) patients, the need for exercise programmes, good nutrition and stress alleviation are recognized as components of discharge planning. However, with few exceptions (DiMattio & Tulman 2003, Garza et al. 2003) the multiple transitions faced by these patients have not been addressed in the nursing literature. There remains a need to identify the perceived needs of patients and family caregivers, and models of service provision that could support both parties in the early and ongoing recovery period at home.

### **Literature review**

Although studies have tracked postdischarge problems among CABG patients, there has been no consistent sampling strategy or methodological approach that would allow prediction of any specific pattern of need to inform discharge planning. Most studies have mapped the range of patient problems using survey techniques (Moore 1994, 1996a, 1996b, Deaton et al. 1998, Ho et al. 2002), conducted postdischarge interviews with varying patient samples (Anderson et al. 1999, Doering et al. 2002) or compared CABG patients' recovery needs with those of other cardiac patients (Jaarsma et al. 1995). A further lack of uniformity lies in the time period studied, with some studies being conducted 12 weeks after discharge (Savage & Grap 1999, DiMattio & Tulman 2003), and others at 6 or 12 months postoperatively (Deaton et al. 1998, Hunt et al. 2000, Duits et al. 2002, Garza et al. 2003). Samuels et al. (1996) interviewed patients after 5 years to identify lifestyle changes after cardiac surgery,

but their sample was considerably younger (mean age = 35) than typical cardiac patients, which makes comparisons with other studies difficult. A few studies have focussed on gender, reporting women reporting higher levels of pain, emotional distress and depression (Meehan et al. 1995, Ai et al. 1997, King 2000, Koivula et al. 2002). However, studies have yet to be undertaken on a large enough scale to ensure consistency across populations or generalizability.

The concerns of CABG patients' family caregivers have attracted some research interest and, despite the lack of methodological consistency, most have found a constellation of problems arising from care-giving responsibilities. These include anxiety, depression, sexual and marital issues, low self-esteem and psychosomatic symptoms, which have been found to persist in spouses especially, up to a year following the cardiac event (Artinian 1991, 1992, 1993, Moore 1994, Monahan et al. 1996, Mahler et al. 2002). Similar effects were reported in a 1989 study of 65 Australian spouses, 25% of whom continued to show clinical depression 12 months after their partner's surgery, but no follow-up study has confirmed this finding (Langeluddecke et al. 1989). Studies in Finland (Engblom et al. 1992), the Netherlands (Jaarsma et al. 1995) and the United States (Archbold & Curzen 2003, Corsetti and Perry 1998) conclude that the recovery period after cardiac surgery does not run smoothly, with many patients readmitted within a year. This body of research and a recent Cochrane Systematic Review of discharge planning for patients over age 60 suggest that appropriate discharge planning can be instrumental in minimizing readmissions, reducing health care costs and improving patient satisfaction with care (Richards & Coast 2003).

## **The study**

### **Aim**

The aim of the study was to examine the range of postdischarge issues, concerns and needs of patients and their family carers following discharge after CABG surgery, and to explore their perceptions of unmet needs 1 year later. The specific research questions were:

What are the issues/concerns/needs of CABG patients and their carers following hospitalization?

To what extent are these related to age, gender and family support?

What actions can be taken before hospital discharge and at a community level to respond appropriately to these issues/concerns/needs?

### **Design**

The study was situated within the interpretive paradigm using naturalistic inquiry, which guides researchers to investigate naturally-occurring phenomena as a basis for inductive interpretation of themes (Streubert & Carpenter 1995). Themes are documented using natural language, and are aimed at capturing the complex nature of the phenomenon under investigation.

### **Conceptual framework**

The study was conceptualized within Doherty and Campbell's (1988) model, called The Family Health and Illness Cycle. This outlines a sequence of families' experiences with health and illness during five discrete periods: health promotion and risk reduction; vulnerability and disease onset or relapse; illness appraisal; acute response; and adaptation to illness and recovery. The model provides a template for understanding family efforts to reduce the risk of illness, manage the onset of illness, and ultimately, adapt to the illness and recovery period as a basis for planning and managing nursing care (Doherty & Campbell 1988). The current study was conceptualized within phase 5 of the model.

### **Participants**

A convenience sample of consecutive patients who had undergone CABG surgery at one tertiary care hospital in Brisbane, Australia and their carers were enrolled in the study. Participants were included if they had undergone CABG surgery for the first time with or without concurrent heart valve surgery, could communicate and understand English, lived within a 2-hour driving distance of the research base, had a willing carer-participant, and gave written consent to participate. Patients meeting the criteria were approached by the cardiac rehabilitation educator to request their participation. Of the 38 invited to participate, eight declined two immediately and six subsequently because of problems attending interviews. The final sample comprised 30 patients and carers.

### **Data collection**

The study had two phases. In phase 1, demographic data were collected and semi-structured individual home interviews were conducted 45 weeks after discharge. Phase 2 involved a follow-up telephone interview approximately 1 year after phase 1 (year 2000), to undertake a 'member check', verifying the accuracy of the phase 1 analysis, and to track experiences over a longer period. In both phases, participants were asked to comment on their health and lifestyle, any concerns they had and any areas of health and lifestyle that might have been improved by different preparation for hospital discharge. All interviews were audiotaped, with verbatim accounts transcribed for analysis. During phase 2 participants were prompted to identify those needs that had been resolved over the first 12 months postdischarge and those that had persisted. Field notes documented background information to contextualize the study, and to record the researcher's (KT) reflections on the information being provided. From the field notes, summary 'memos' were constructed, recording initial interpretations and ideas for further interview questions and prompts.

### **Ethical considerations**

Approval for the study was granted by the Human Ethics Committees of both the hospital and Griffith University. Participants were given a written description of the study and signed a consent form to participate after receiving assurances of anonymity and confidentiality.

### **Data analysis**

Data were analysed using thematic content analysis, in which all initial themes were compared with all others. Field notes were read in conjunction with interview transcripts to triangulate data and to gain a broader picture of the emerging themes. Data reduction occurred throughout phases 1 and 2 until there was clarity and consistency of emerging themes.

## **Findings**

The 30 patients included 22 men and eight women, whose average age was 65 years. The majority (73%) were married. Four others were widowed and two couples lived in stable partnerships. Most were Australian born, with only one Indigenous Australian. Four were migrants: two from the UK and one each from Germany and New Zealand. Twenty-six of the patients had CABG surgery only, while the others also had replacement of the mitral or aortic valve. One had six bypass grafts; 12 had four; eight had three grafts and one had a single graft.

The most common donor graft site was the left internal mammary artery. All patients except one underwent standard bypass surgery in which they were placed on a circulatory pump bypass during surgery. Of the 30, nine patients had not experienced cardiac symptoms prior to their current episode. Carers were comprised of 27 females and three males whose average age was 59 years.

Five major themes emerged from the patient data, each having a number of sub-themes. Major themes included: Heart surgery as a wake-up call; Making the decision to have surgery; Personal changes due to surgery; Shifting expectations and Discovering pathways to recovery. From the carer data, the major themes to emerge were: Events surrounding another's heart surgery; Adjusting to the surgery; Personal changes due to surgery and Discovering pathways to recovery.

## **Patient findings**

### **Heart surgery as a wake-up call**

For almost half of the patients, the cardiac episode leading to surgery was an unexpected and major shock. Many experienced difficulty coming to terms with the suddenness of the event. They, and others who had previously experienced cardiac problems, spoke of resentment and the 'wake-up call' of seeing themselves as no longer young and healthy:

it gave me a bit of a wake-up call in 1988 and 1991, but within weeks I was back doing the same damn thing again twice as hard, twice as fast, forty feet tall, bullet proof. This time, it frightened the bloody heck out of me and I was thinking about my grandchildren and the rest of them and of course, Barb and the kids and it just isn't worth it. (P5)

### **Making the decision to have surgery**

Individuals dealt with the need for heart surgery in their own ways and, while some managed alone, most appreciated support from their partner, family and/or friends. A few denied the situation, expressing a desire to go back to work, ignoring the pain, or

refusing to change their activities. Others were more accepting, knowing from previous cardiac episodes that they would eventually need surgery. For one-third of participants, the decision to have surgery was a critical, life or death decision, and they talked about facing death for the first time. Cardiac surgery was recognised as their only means of survival, so their consent to surgery was immediate:

Well, I didn't have much choice at the end of the day what was I going to do? Lie down and die I mean there was no way in the world I was going to do that, so it wasn't a matter of consenting, it was just a matter of 'get on with it', you know, 'do it and I'll sort it out as I go along'. (P5)

## **Personal changes due to surgery**

### **Pain**

All patients experienced some pain as a result of the cardiac surgery, describing it using phrases such as tenderness in the chest; like a fire in the chest; stabbing pain; a sunburnt feeling; a soreness and feelings ranging from a numbness to an irritation. One person put it this way:

it was pretty horrific to start with, but I think the worst thing about the pain, it's sort of different pain to anything you've ever had before. And I think probably not understanding the pain, and not sort of knowing what it means, you think to yourself, well what is this, why does it feel this way? (P17)

While some chest pain was expected, many reported chest wound, leg wound and 'other pains' or combinations of these three types, which was unexpected. Some explained that they had received no preparation for pain other than chest pain. Women seemed to experience much less chest wound pain than their male counterparts, yet they described other pains like 'chest wall pain' or pain that was 'indigestion-like' in intensity.

A number shared their strategies for minimizing pain, including repositioning, deep breathing and complementary therapies such as music.

### **Physical changes**

Patients spoke of changes in their physical capabilities, comparing these before and after surgery. Accounts ranged from physical improvements as a result of surgery to disappointment with surgical outcomes:

Yes, I have felt really frustrated, because I'm a really, really active person and I like to have things just so. There are little things that I can't do, like unscrewing something, and, you know, they've only unblocked the artery and they haven't cured the disease, and then you've got this ongoing problem to manage. (P31)

Nearly half of the patients described unexpected complications, ranging from urinary problems to shakiness in one hand, constipation, pneumonia and infected chest wounds. Other physical problems included extreme tiredness, difficulty sleeping, weight loss and taste and appetite loss. They also described a heightened sense of

awareness of a range of physical changes during their recovery; for example distress over the site where vein graft/s were removed, or concern about changes in general appearance. They seemed highly attuned to changes, and almost hypersensitive to their bodies:

I was surprised in such a short time that I have lost nearly all muscle tone in my legs and I don't really like it, I don't look or feel the same. (P31)

I notice my voice is more not as strong and inclined to be a little bit old man's voice, sort of thing, you know. But it's very, very weak. (P25)

### **Heart surgery as a financial burden**

Many patients raised the topic of the financial burden of the illness. The actual cost of surgery, timely payment of bills and the difficulty in concentrating on budgeting were of considerable concern:

The bill had a 35% discount if I paid in 30 days and it was here when I came home. Now the first week, you don't feel like doing anything and then it takes another week to get yourself organised and start looking at this stuff well 30 days is just about gone. (P6)

The bills well, I felt I kept looking at them and I didn't know what to do with them I've just got to pull myself together and do it, you've got to help yourself a bit, you've got to force yourself to do it. (P15)

### **Shifting expectations**

Patients spoke about the loss of their previous lifestyles. Some reported anger and frustration because they could not undertake their usual daily living activities, while others were disappointed that they could not return to work and reported feeling depressed over having to rely on others. One woman described her fear as being 'scared to be left on my own during recovery', especially if something unexpected happened to her. Another described her moment of coming to terms with the reality:

I knew all this stuff was coming on the weekend and I wanted to do things like I'd normally do it, and I can't do it myself, and I asked the kids to do a couple of little chores for me and they did the usual teenager stuff, they rolled their eyes and that, I just lost it(P32)

### **Heightened body awareness**

Existing co-morbidities were exacerbated or imposed extra difficulties during recovery. Patients described 'heightened body awareness' as their heart rhythms changed immediately after surgery, nausea accompanying a fast heartbeat, or a thumping feeling in the chest. One man reported hearing the sound of his new heart valve ticking, which took him by surprise.

### **Worrying about the future**

Many thought about the future. While some were quite clear about their expectations, others feared the unknown and its uncertainties. Several people knew that they would 'be opened up' to have surgery again, given that bypass grafts have a life expectancy of only around 810 years. These were real fears as especially younger patients may require another surgical intervention at some stage. They worried that they would never be fully restored. One expressed dismay that his work life might be over. Others were concerned about recurring pain. Some were resolute in remaining positive and optimistic about their future, but most established more immediate, short-term goals:

I've been telling everyone that comes in here that I am going to buy a glass cage, I'm going to put it up in my lounge and put that purple huggy (pillow) in it to remind me that I'm never going back to have another one. (P24)

### **Discovering pathways to recovery**

Some patients considered their immediate home and family environment critical to their recovery:

normally I am on my own, but the first week they stayed with me, and my daughters phone me every day, and never miss, I get a phone call. And (name) has been a wonderful help to me with the car, with appointments to the doctor and to the bank and to the GP and all those things, and getting me provisions. (P3)

Others expressed concerns at being a burden for their carers, despite needing support. They commented on not being able to cope alone without the support of children, with daughters assuming most of the support role. Yet not everyone had family carers, and three women had to hire home helps for assistance with walking and domestic work. Those with support from family and friends seemed to have a more positive view about their recovery than those who needed to find and pay for help. Patients also supported each other, particularly during hospitalization, one suggesting that they should form some type of community club or network to assist one another during recovery and to overcome isolation:

I think having been on my own has forced me to do things probably sooner and be more independent than I would have if I had had something, someone living with me to lean on. I initiated getting paid help while I was in hospital. Well, you know, you really need somebody for a couple of weeks and I was really a bit astounded that, you know, that I didn't have anybody, so I decided that I'd do something about it. Yes, and I think you definitely have got to have that help and it does give you the confidence. (P17)

### **Carer findings**

All but one of the carers were family members, most being wives or daughters. The major themes of their experiences are described below.

### **Events surrounding another's heart surgery**

Where the need for cardiac surgery was urgent, this came as a shock to carers. Their reactions revolved through confronting the need for surgery; experiencing the reality



of surgery and postoperative relief. Confronting the need for surgery depended on whether the experience was expected or not, with unexpected cases having the greatest impact. For the others, surgery was followed by feelings of relief that something was being done to help the patient.

### **Adjusting to the surgery**

Carers felt a strong sense of responsibility in being a 'watcher' or 'minder' during the recovery period. Most thought they should be with their relative at all times, to guard against overexertion. One was concerned about whether her partner was still breathing when he rested, and others remained similarly vigilant, not wanting to let the person out of their sight. They described a willingness to do anything, however extreme, if it would help. Some moved into the patient's residence for the initial post discharge period, and some became preoccupied with things like food preparation, seeking something to mark their willingness to help, even when this meant major lifestyle adjustments:

You make sure that he's breathing and that sort of thing. Checking on him and making sure that he was just sleeping. (C16)

I go with him when ever I can. Well, he tells me where he's going and if he's not back within a certain time I certainly go looking for him. (C20)

Carers were highly sensitive to changes in their relatives' progress, especially related to sleeping problems, pain and insecurity issues. Many described the difficulties of sharing a bed with a partner, coping with wakefulness, positional changes and going to bed early. They expressed concern and lack of confidence in helping with their partners' pain, and tried a number of home remedies ranging from aloe vera cream to hot water bottles.

### **Personal changes due to surgery**

All carers experienced role changes. Some required major personal adjustments, for example, moving into the partner's home; however, this doubled household responsibilities and often meant absences from work. Many took on new roles around the house, including cooking, paying bills, mowing lawns and gardening:

I've been doing the cooking and I hate cooking, because (name) loves cooking, so he used to do the cooking and I'd do the washing and wiping up and all the housework. So since he has been home I have been doing it all. I won't let him do anything. (C1)

Normally he does the bulk of the mowing and things and I've been trying to do that he couldn't, I know, physically he was told not to. I've dropped a few hours and swapped days around and things like that with some of the other staff and they've been very helpful. (C6)

Several carers described positive changes in their relationships, drawing closer together for walks or sharing a meal, but most described the experience in more negative terms related to sleep disturbances, emotional changes, and in some cases loss of freedom:

I got very tired, very tired and very emotional and I'm still that way. While he was in hospital I didn't sleep a great deal. When he came home the first week it was adjusting to the way he was sleeping, because he was just sleeping off and on (C4)

They reported anxiety, stress and worry about what could go wrong. This led to feelings of isolation, especially if there was friction with other family members who may not have been available to assist with care. They had little knowledge about pain, changing roles, slowed pace and changes in their partners' appearance. Finances were a concern, especially when reimbursements from medical funds were overdue, or where there was loss of income. One woman developed chest pains, which she attributed to the stress of caregiving. In another case, marital problems intensified as a result of the illness and surgery, and several carers expressed a need for respite, saying that at times 'things just got too much':

I don't know how I'll cope as time goes on because I get frustrated, I had to get outside and either just get in the car and go down the shopping centre. (C20)

### **Discovering pathways to recovery**

All carers felt supported by others, especially family and friends. Private and public community health and laboratory services and family GPs were also rated highly. A few suggested that having access to additional services, such as counselling or telephone support, would have helped during the recovery period. Many suggestions were made for more helpful discharge preparation. The majority appreciated the hospital lectures on nutrition, relaxation, carer support and diabetes mellitus, describing these as beneficial. A small number were critical, stating that the sessions needed to incorporate information on specific types of diets in the nutritional component, and more detailed information from the pharmacy about the actions and side effects of medications. One carer appreciated the group sessions more than individualized information, remarking on having learned that people who need bypass surgery have little in common. It brought home to him that 'there's no recipe that will prevent it happening to you'.

Mutual support was rated highly, with those who had friends, family or neighbours who had undergone bypass graft surgery sharing the benefits of having an experienced confidante. A small number of carers connected with others in hospital, finding this helpful. In discussion groups, they developed a sense of shared experience rather than the isolation of being alone in their experience:

I thought it was really good I learnt a lot. Just hearing other people's stories helps doesn't it? (C31)

### **Discussion**

The findings fit well within the stage of adaptation and recovery of Doherty and Campbell's (1988) Health and Illness Cycle, given that major adaptive responses were occurring in both patients and carers. The impact of surgery, especially when it was unexpected, proved to be enormous for both patient and carer, and this requires further nursing consideration. No other CABG studies were found that reported this

feeling of being overwhelmed by the unexpectedness of the sudden decision to proceed with CABG surgery. People being confronted with the need for surgery are forced to come to terms with the situation rapidly and, in some cases, must decide within hours whether to proceed with surgery or not. This is compounded by the profound experience of pain they encountered. Other researchers have also reported that patients experience continuing pain after cardiac surgery (Jaarsma & Kastermans 1997, Corsetti & Perry 1998, Anderson et al. 1999, Savage & Grap 1999, Van Kooten 1999, Ho et al. 2002, Westerdahl et al. 2003).

It was interesting that more than half of our patients had postoperative complications, which may have exacerbated the impact of physical and psychological sequelae. Earlier research by Tack and Gilliss (1990), Moore (1994), Mathew et al. (1996) and Redeker et al. (1996) examining the early recovery period after CABG surgery also identified complications and physical problems. Complications described in more recent research, include cardiac arrhythmias (Place et al. 2002, Stanley et al. 2002, Archbold & Curzen 2003), wound infection (Konuralp et al. 2002, Olsen et al. 2002, Risnes et al. 2002, Kim et al. 2003, Tavalacci et al. 2003), stroke (Likosky et al. 2003) and pulmonary impairment (Hulzebos et al. 2003, Westerdahl et al. 2003).

The major adjustments experienced by carers created ongoing anxiety and stress, because of relationship adjustments, adaptation to a new role, or financial problems. The effect on family life was significant. As expected, the surgery evoked concern about the future in both patients and carers, which concurs with Jaarsma et al.'s (1995) findings.

In the current study, support systems were a critical factor in allaying patients' fears of feeling isolated. All comments from participants point to the need for appropriate discharge preparation. While most people praised the efforts of hospital staff, suggestions were made for improving services. Not surprisingly, other researchers also highlight the importance of adequate preparation for transition to home after CABG (Doering et al. 2002, DiMattio & Tulman 2003, Garza et al. 2003).

The study identifies issues for consideration in clinical practice, especially in relation to emotional preparation for surgery immediately after the patient has been informed. The prevalence of ongoing pain, even up to 1 year after surgery, should also be considered when developing anticipatory guidance. Pain management information, as suggested by other researchers (Henderson & Zernike 2001), should be comprehensive, address realistic expectations and symptom management, yet be written in language that is easily understood, and it should be provided as soon as possible, just before or immediately after surgery. After discharge, the provision of individual hospital- or community-based telephone chat/help facilities which are available 24 hours a day could also be extremely beneficial in the early recovery when patients and carers are coping alone with the highs and lows of recovery (Henderson & Zernike 2001).

Carers clearly required guidance on their roles and ways to be helpful, strategies for monitoring patient progress without being overprotective, and some acknowledgement of the strains they may encounter in caring for others. They needed specific, local information on the range of support services available in their community, as well as information on financial matters. Minimal interface exists

between the health care system, its professionals and patients/families to ensure smooth transition from hospital to home and community care (Richards & Coast 2003).

Our findings suggest that future research should explore patient and family experiences of 'unexpectedness' of treatment decisions and the probable interventions/treatment options available or required, comparisons of complementary therapies, gender comparisons of CABG patients and their recovery experiences, particularly in relation to pain and pain alleviation, differences in activity limitations, and rehabilitation exercise programmes. Further study could give insight into the heightened sense of awareness of physical changes highlighted in the current study and the sense of aloneness that emerged as an important part of patients' experiences. These could be further explored with other CABG patient/carer groups to ascertain whether they are peculiar to cardiac surgery patients. It would also be interesting to assess the impact of residential and non-residential support systems, comparing findings with other groups of postsurgical patients.

### **Study limitations**

A major criticism of this study is the inability to generalize the findings to a broader population of cardiac surgical patients because our sample was small and was recruited from a single health care centre. Naturalistic inquiry involves intense investigation with individuals in their usual settings, thus providing in-depth data on those participants but no generalizability.

### **Conclusion**

People undergoing CABG surgery, and those who care for them after discharge, will encounter many issues and changes to their usual daily routine. They may have unmet needs and health services may not be sufficiently seamless or adequate to anticipate and address these needs, especially those for support for family carers in what may be one of the most stressful times of their lives.

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