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Using illness trajectories to inform person-centred, advance care planning

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What you need to know

- Most patients with progressive illness follow trajectories of decline, previously identified as rapid (typically progressive cancer), intermittent (typically organ function), or a gradual decline from a low baseline (typically in older age, neurological disease, or dementia). Multimorbidity is increasingly common and follows a distinct fourth trajectory
- An understanding of the dynamic multi-dimensional trajectories of patients with progressive illnesses helps clinicians consider their individual holistic needs and have meaningful conversations with patients and families about advance care planning. Discussing potential events, interventions, treatments and care helps everyone plan for specific challenges and manage the inherent uncertainties.
- In patients with an acute deterioration in health (for example from an infection), considering the main underlying illness trajectory helps guide shared decision-making about realistic current and future treatment and care options.

Illness trajectories of people in the last years of life

Patients diagnosed with a serious illness often ask doctors about prognosis as a way into talking about what life might be like in the future. [1, 2] The main point of identifying the most relevant illness trajectory for a patient is to help them with understanding and discussing their likely illness course while we acknowledge the inherent uncertainties involved. Referring to experiences of people in similar situations provides a context for exploring what matters to each person as we discuss shared decision-making and make plans for their future treatment and care. Illness trajectories offer conceptual maps of archetypical patient journeys in the final years and months of life. Trajectories have been used clinically for nearly 20 years to aid timely identification and assessment of people for a palliative care approach [3, 4] and more recently in population-based studies of access to palliative care. [5, 6] Person-centred conversations are central to meaningful advance care planning and discussing a possible future illness trajectory can be a useful part of the process. [7, 8]

What are the main illness trajectories?

Three main illness trajectories of physical decline described from empirical research in the UK and USA are – rapid decline (typically progressive cancer), intermittent decline (typically with organ function), or a gradual decline from a low baseline (typically in older age, advanced neurological disease, or dementia). [3, 4, 9] Evidence from qualitative research exploring the multidimensional experiences of people living and dying with different life-shortening illnesses found that trajectories of physical decline are accompanied by concomitant psychological, social, and spiritual dimensions. These data emerged in a synthesis of 12 longitudinal studies including over 1200 in-depth, serial interviews with people who had cancer, declining organ function, or frailty and their family carers from diagnosis to death and bereavement. [10] Findings were confirmed in research involving older people with frailty, and with patients and families after major stroke. [11-14]

Figure 1 is a current version of the three well-established, multidimensional trajectories of declining health described in our 2017 BMJ analysis. [15] As a rule of thumb, in patients with advanced cancer social functioning often declines with physical deterioration, whereas psychological and spiritual wellbeing tend to fall together at key times: around diagnosis; at discharge following treatment; as the illness progresses; and in the last weeks or days of life. By contrast, people living with declining organ function described how their social and psychological wellbeing mirrored changes in physical functioning, while spiritual distress fluctuated more and was modulated by factors like a person's capacity to remain resilient. People with advanced frailty, dementia, neurological conditions or a major stroke typically talked of gradual physical decline from a low baseline. Psychological and spiritual wellbeing could be affected by changes in social circumstances or an acute physical illness. Looking back, family members sometimes identified a global fall in social, psychological and occasionally spiritual wellbeing before death.

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3 These multi-dimensional trajectories feature in many undergraduate and
4 postgraduate textbooks, and have been widely cited in clinical and research articles
5 internationally. These graphic presentations are useful aide memoirs illustrating the
6 holistic, lived experiences of patients with deteriorating health. Awareness of a likely
7 “big picture” enables clinicians to anticipate, assess and manage the dynamic
8 multidimensional care needs of patients and families.
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10

11 **Figure 1 here**

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14 More recent research with the growing numbers of patients and families living with
15 multiple health conditions (multimorbidity) points to an additional trajectory of decline
16 which has elements of the three established trajectories but distinctive features. [16-
17 17] Fluctuations in health from new diagnoses and/or complications of existing health
18 conditions differ from the gradual physical decline associated with progressive frailty.
19 People with multiple conditions talked of living day to day as they managed the
20 cumulative effects of their various illnesses on the four dimensions of wellbeing.
21 (Figure 2) Patients and families often thought changes were part of ageing. [18] Social
22 concerns could relate to the challenges of managing fluctuating and unpredictable
23 illnesses which sometimes triggered an emergency hospital admission. Patients had
24 difficulties accessing practical support without a recognisable serious illness even
25 though people with advanced multimorbidity have a poor prognosis. [19, 20]
26 Psychological concerns seemed to reflect periods of greater anxiety or depression
27 associated with physical or social health changes alongside ongoing mental health
28 problems. Spiritual distress was multifactorial and described as loss of control, lack of
29 meaning and purpose or the demands of coordinating care in the face of multiple
30 illnesses and medications. [18] Multimorbidity occurs at a younger age in people from
31 socioeconomically deprived areas and is common in people from minority ethnic
32 communities. These groups receive less holistic palliative care and care planning. [16,
33 21] If a multimorbidity trajectory is considered, this can aid holistic assessment and
34 care planning but multiple conditions and their different impacts mean individual
35 patients and their families have varied experiences and priorities.
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43 **Figure 2 here**

44 **How can we use illness trajectories to improve patient care?**

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48 A background knowledge of these four archetypical trajectories allows the clinician to
49 map an individual patient’s situation to broad patterns of illness and dimensions of
50 wellbeing. General practitioners and other doctors often use pattern recognition to aid
51 diagnosis, and we can recognise trajectories of decline and use these to guide patient
52 care. [22] Models of integrated care across different diseases and dimensions of need
53 are vital to prevent silos of care and is established good practice in primary care.
54 Sharing an understanding of illness trajectories with patients and families can help
55 clinicians explore people’s priorities, for example at a medication review or when
56 making shared decisions about further investigations or treatment. Douglas has
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3 advanced lung disease as his main health problem alongside heart failure and early
4 dementia so is probably following a multimorbidity trajectory. His wife, Ruth, has lived
5 with multiple health conditions for some time but is increasingly frail so her doctor
6 might decide that a frailty trajectory is now the most helpful to guide her care.
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9 Holistic assessment across the four dimensions of wellbeing highlighted in this
10 approach enhances doctor-patient relationships and is a core aspect of value based
11 health and care. Realistic medicine requires clinicians to share the likely benefits, risks
12 and harms of treatment in the light of an individual's most relevant illness trajectory.
13 [23]
14

15 **Illness trajectories as a useful tool in person-centred, advance care planning**

16
17 There is growing support for a broader approach to advance care planning that takes
18 account of illness complexity and outcomes of importance to individuals. [7, 8] Talking
19 about what has happened for people with similar health problems helps patients and
20 families think about potential future changes and feel supported to talk about what
21 options might be best for them. [24] Clinicians can use trajectories to identify people
22 most at risk of a health care crisis or poorly coordinated care for care planning by
23 recognising an evolving pattern of illness or an acute change in one or more
24 dimensions of need.
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28 Advance care planning has four steps: timely identification of declining health;
29 multidimensional assessment of the person's current situation and probable main
30 illness trajectory; care planning conversations based on the person's values,
31 preferences and priorities; and effective care coordination by recording, sharing and
32 reviewing individual care plans with other professionals and services. These steps are
33 repeated as the person's situation and needs evolve. (Figure 3) By recognising typical
34 patterns of decline, clinicians can offer patients and carers proactive, well-coordinated
35 care for months or years not just in the final weeks before death. Table 1 has links to
36 tools from national organisations, primary care, palliative care, and geriatric medicine
37 relevant to each step.
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42 **Figure 3 here please.**

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44 **Step 1. Identification of the patient:** Early identification of patients allows us to
45 identify people most at risk of poorly coordinated care and start proactive,
46 individualised care planning. This may be when a serious illness is diagnosed or a
47 person's health starts to decline gradually or more rapidly from general frailty or
48 multiple conditions and complications. Triggers for offering care planning linked to
49 illness trajectories happens long before reaching the point when a person is no longer
50 responding to treatment of their health condition or is entering the final weeks of life
51 and the main focus is palliative care. At the same time, trajectories prompt holistic
52 assessment of anxiety or social concerns alongside managing an acute exacerbation
53 or a complication of declining organ function. Timely identification for care planning is
54 an important core skills for GPs and hospital doctors. The "Surprise question": *Is this*
55 *patient sick enough to die in the foreseeable future?* has helped clinicians start
56 thinking about patients who might deteriorate but multimorbidity and changing patterns
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3 of treatment and care mean individual patients may die at different stages along each
4 trajectory. [25, 26] Validated tools based on burden of illness and clinical indicators
5 are used increasingly to identify people with diverse illnesses and in different settings.
6 [27, 28]
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9 **Step 2. Holistic Assessment:** Illness trajectories remind us that patients and carers
10 often experience dynamic physical, social, family, psychological and spiritual concerns
11 and needs. Making a broad “situational diagnosis” using a knowledge of the most likely
12 illness course helps ensure holistic needs and concerns are addressed alongside
13 physical problems. For example, frailty indices based on a Comprehensive Geriatric
14 Assessment (CGA) can help professionals evaluate the patient’s level of vulnerability
15 based on their overall health and situation. [29, 30] Alternatively, a structured carer
16 assessment can target family support. [31]
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20 **Step 3. Care planning:** Then, the clinician can discuss patient and family ideas,
21 concerns and expectations, and talk with them about what might be important if a
22 possible event or change were to happen. This conversation is guided by the patient’s
23 main illness trajectory while always acknowledging the inherent uncertainty of
24 advanced illness. [32, 33] A way of approaching this is to say; “It is hard to know
25 *exactly what will happen with your illness or how quickly things might change, but*
26 *would it help to talk about what can sometimes happen for people with health*
27 *conditions like yours?* Knowing patients with incurable, progressive cancer often
28 experience psychological and existential distress at certain times, we can anticipate
29 this and offer relevant, timely support. If a patient has a trajectory of declining organ
30 function or multimorbidity, we might choose to start talking about predictable events
31 such as hospital admissions and how making emergency care plans to be recorded
32 and shared with other professionals can improve care. Proactive care planning helps
33 people living with dementia and their carers think about how they will manage
34 decisions in the future but conversations about what could happen in the shorter term
35 can be a good starting point. Recognising patterns of changes guides primary care
36 staff in prioritising patients and helps with workload pressures. [34] As the patient’s
37 health conditions, illness trajectory, situation, values and preferences evolve, we adapt
38 goals of care in discussion with them and their family carers. Language acceptable to
39 patients such as “thinking and planning ahead” in Scotland or “an added layer of care”
40 in Canada can facilitate public engagement with planning future care. Carers may
41 have additional worries about their own health and role so we assess and address
42 their needs too. [31, 35] Care planning resources include structured processes such
43 as ReSPECT UK and PREPARE in the USA. [36, 37] The REDMAP communication
44 framework (Box 1) offers an evidence-based approach to guide clinicians in having
45 meaningful conversations about advance care planning with six steps and positive
46 language that is clear and honest. [24, 38]
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57 **Step 4. How to coordinate care:** Electronic care coordination systems are
58 increasingly common in the UK [39] and internationally to share patient information
59 across teams, services and settings. In one region of Spain, palliative care, primary
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3 care and geriatric medicine teams all use the same shared plan (PIIC). [40] Such
4 systems should allow relevant clinical information to be updated, shared and accessed
5 electronically by all key professionals. In the USA, the POLST process is a patient held
6 summary that is transferrable across settings. [41] A clear summary care plan should
7 highlight that the patient might benefit from consideration of their main illness trajectory
8 when receiving unscheduled and emergency care.
9

10 11 12 Limitations of the typical trajectory approach

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14 Using illness trajectories in clinical practice and education merits further study as this
15 has not been done formally. The extent to which this approach is applicable to different
16 countries, socioeconomic positions, ethnic and religious groups is unknown. Different
17 components of distress can be linked and difficult to separate. People may react in
18 different ways to illness, and many external factors can impinge on more typical
19 patterns of illness. New diagnoses and circumstances may intervene and people's
20 priorities change.
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26 27 28 **Conclusions**

29 Integrated, person-centred care is essential for all people living and dying with serious
30 illnesses or multiple advanced conditions. Trajectories derive from extensive evidence
31 about people's lived experiences. An acute event, new diagnosis or change in
32 circumstances can trigger an assessment across all health conditions and dimensions
33 of need. The clinician can talk with the patient and family about planning appropriate
34 care tailored to their main illness trajectory. Waiting to establish a "poor prognosis" or
35 that death is approaching neglects important opportunities to give people holistic care
36 aligned with the course of their illness. Sharing care plans electronically across all care
37 settings reassures patients and carers, and helps clinicians make realistic, value-
38 based treatment and care decisions in an emergency. Many patients and carers stand
39 to benefit from well-structured and proactive care and advance care planning based
40 on the anticipated course of their underlying health conditions. In our experience, this
41 approach fosters holistic care, patient understanding and engagement with care
42 planning.
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Table 1. Resources and tools for professionals

Key steps	Resources
1. Identification (individual or population screening)	<ul style="list-style-type: none"> * Supportive & Palliative Care Indicators Tool (SPICt available in multiple languages and as a version for low income settings) * Proactive Identification Guide (PIG) * Palliative Care Needs (NECPAL) * SENS Structure (Switzerland) * Clinical Frailty Scale (Canada) * Electronic Frailty Index (UK)
2. Multidimensional assessment (patient and carer)	<ul style="list-style-type: none"> * Daffodil Standards (Royal College of General Practitioners, UK) * Integrated Palliative Care Outcome Scale (IPOS) (UK) * Gold Standards Framework (GSF) * Comprehensive geriatric assessment (CGA) * Frailty indexes based on a CGA (Frail-VIG index) * Palliative Care Phase (Australia) * Carer Support Needs Assessment Tool (CSNAT) (UK)
3. Planning (shared decision-making)	<ul style="list-style-type: none"> * Healthcare Improvement Scotland ACP Toolkit * Using REDMAP (Royal College of Physicians & Surgeons of Glasgow, UK) * ReSPECT process (UK) * PREPARE (USA)
4. Coordination (record, share, review)	<ul style="list-style-type: none"> * Coordinate My Care (London, UK) * Key Information Summary (Scotland) * PIIC (Catalonia, Spain) * POLST process (USA)

Box 1. Using REDMAP in person-centred, advance care planning discussions

REDMAP framework	
Ready	Can we talk about your health and care? Who should be involved?
Expect	What do you know? Do you want to tell/ask me about anything? What has changed? Some people think about what might happen if...
Diagnosis	What we know is... We don't know... We are not sure ... I hope that, but I am worried about... It is possible that you might.... Do you have questions or worries we can talk about?
Matters	What is important to you and your family? What do you like to be able to do? How would you like to be cared for? Is there anything you do not want? What would (<i>name</i>) say about this situation, if we could ask them?
Actions	What we can do is... Options that can help are.... I wish we could..., can we talk about what is possible for you... This will not help because.... That does not work when...
Plan	Let's plan ahead for when/if.... Making some plans in advance helps people get better care.

Information and resources for patients, carers and the general public

UK public information websites about care planning, serious illness, death, dying and bereavement:

[NHS Inform – thinking and planning ahead \(NHS Scotland\)](#)

[Dying Matters \(England\)](#)

[Good Life, Good Death, Good Grief \(Scotland\)](#)

[Marie Curie – care and support through terminal illness \(UK\)](#)

[Macmillan Cancer Support – cancer information and support \(UK\)](#)

[Age UK – information and advice \(UK\)](#)

[How to live and die well: understand what might happen and plan.](#)

This short video is for everyone, explaining illness trajectories. It's for people who are well just now to think ahead. It is also for people who currently live with progressive illness. It's also for family members and carers of those who are ill, and who want to learn what can happen in the future so they can plan ahead

[Strictly Come Dying](#)

This light-hearted video discusses the different illness trajectories as though each were a dance with a particular tempo and complexity. Just as knowing the different dance steps will help someone dance well, understanding typical physical and emotional sequences of various illnesses can help people live and die well.

[SPICT-4ALL \(Supportive and Palliative Care Indicators Tool for All\)](#)

This version of the SPICT in lay language aims to help everyone recognise and talk about signs that a person's overall health may be declining so that those people and their carers get better care and support whether they are at home, living in a care home or in hospital. Also available German and Spanish.

How this article was written

The authors are general practitioners from France and Australia, a geriatrician from Catalonia, a social scientist, a patient representative, a palliative medicine specialist and medical educator, and a professor of primary palliative care from the UK. We drew on extensive qualitative research with patients and families and extended the concepts of physical, social, psychological and spiritual dimensions described in 2005 and 2017 as well as proposing a distinctive multimorbidity trajectory. We also reviewed broader patient experience research internationally, and interventions in many countries that provides guidance on palliative care throughout Europe, Australia, and America to inform this educational resource.

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3 We also reviewed publications on advance/anticipatory care planning, symptom
4 burden, person-centred care and shared decision-making, and clinical
5 trajectories in multimorbidity. We have refined these concepts with colleagues at
6 international primary care, palliative care and geriatric medicine conferences.
7 MK is an expert in researching the experiences of patients and carers, and
8 SMcP contributed a public involvement perspective. SAM and JA prepared a
9 draft, and all authors then contributed to writing the subsequent drafts and the
10 final submitted paper. SAM is the guarantor.
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16 **How patients were involved in creating this article**

17 SMcP, a co-author of this paper, was patient /carer representative on many of the
18 qualitative interview studies that form the evidence base for illness trajectories and
19 she confirms the value of sharing information based on patterns of decline in a
20 person's underlying health conditions. Edinburgh University studies all included
21 active patient and public involvement (PPI), with researchers working alongside
22 patient and carer groups to design the studies, recruit participants, analyse key
23 themes and disseminate findings. Members of these groups thought that
24 illustrating the possible changes that can happen in different illness "trajectories" of
25 decline in diagram can help patients and families understand their illness better,
26 and plan for possible events and challenges.
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28 The REDMAP framework for care planning conversations was developed by KB as
29 part of a Macmillan Cancer Support funded quality improvement project that had
30 patient/carers consultations embedded throughout.
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38 **Education into practice**

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- 41 • In my general/family practice, do we have effective processes to identify
42 patients with declining health based on recognition of their main illness
43 trajectory and its associated clinical indicators/triggers?
44
 - 45 • How are key staff members in our team enabled to start and/or continue timely
46 conversations with patients and families about advance care planning?
47

48 Further guidance: [RCGP and Marie Curie UK General Practice Core Standards
49 for Advanced Serious Illness and End of Life Care.](#)
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54 **Example of clinical scenario**

55 *Douglas, aged 73 is discharged home from hospital following a second recent*
56 *admission for an exacerbation of advanced chronic obstructive pulmonary disease*
57 *(COPD). He also has worsening heart failure and early dementia. His wife, Ruth,*
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has multiple underlying conditions including arthritis, depression, hypertension and a previous stroke contributing to her progressive frailty. Ruth phones the GP practice to say she is worried about how they will cope at home. She is also your patient. What could you do?

- Arrange a time to talk about planning current and future care with Douglas and Ruth together and/or individually, if they would prefer that.
- Explore their worries and what they know and expect to happen with their health and care. Having identified a main illness trajectory of multimorbidity (Douglas) and frailty (Ruth), you can discuss treatment and care options informed by these patterns of declining health. Douglas is at risk of further acute exacerbations of his COPD and/or heart failure while Ruth might have a fall or deteriorate with an infection. Anxiety, social isolation or financial worries could be other concerns for them both.
- Talk about the benefits of having a personal health and care plan for future changes that could happen to either of them shared with other teams and services, including emergency services and local hospitals; explain how this is put in place.
- Use your 'situational diagnosis' to review their clinical care plans and medications and make adjustments in line with progressively shifting goals of care over time.
- Discuss a self-management plan with options to try when either of them has an acute illness or health crisis that might be anticipated from their main illness trajectories, and give clear advice about how and when to seek help best suited to their likely needs and preferences from the primary care team and the urgent care/emergency services.
- Encourage use of their own support networks, and community resources for people living with their underlying illnesses.
- Find out what is most important to Douglas and Ruth if one or both of them get more unwell or seriously ill.
- Explain that certain interventions and treatments will not work or can leave people with their health conditions in poorer health. Make a clinical assessment of treatment outcomes based on their current situations and illness trajectories. Offer to record a recommended emergency plan for each of them with details of interventions they do not want or that would not work for them which can be updated if/when things change.
- Find out if they have talked with family or friends about choosing people to have a Power of Attorney for them (legal proxy decision-makers). Douglas is at risk of losing decision-making capacity due to progressive dementia and Ruth could have a further stroke.

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Conflicts of Interest

We have read and understood [BMJ policy on declaration of interests](#) and declare we have no conflicts of interests to declare.

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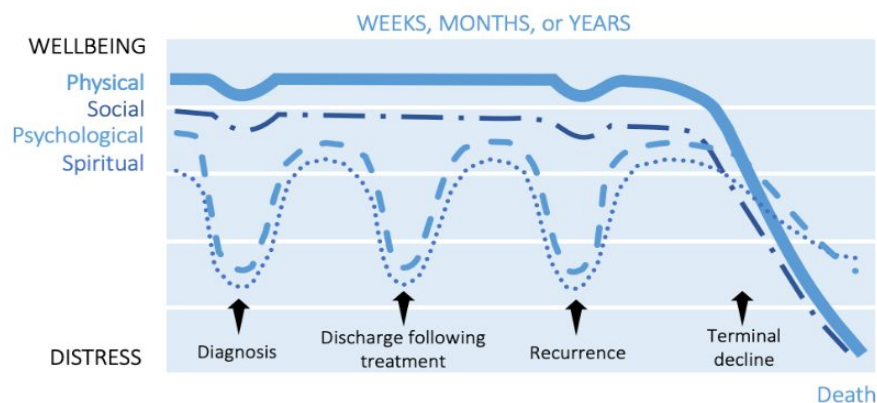
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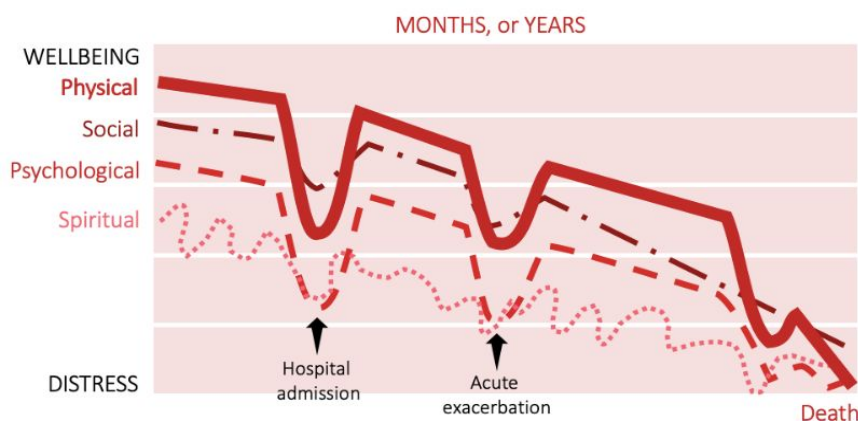
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Figure 1. Physical, social, psychological and spiritual wellbeing in rapid, intermittent and gradual trajectories of physical decline.

A) Wellbeing dimensions in people with RAPID DECLINE (typically progressive cancer)



B) Wellbeing dimensions in people with INTERMITTENT DECLINE (typically declining organ function)



C) Wellbeing dimensions in patients with GRADUAL DECLINE (typically in advanced frailty, dementia, neurological conditions, or major stroke)

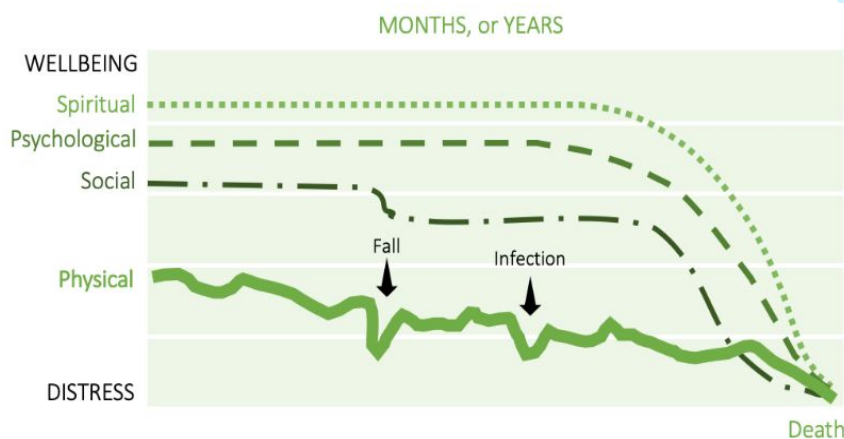
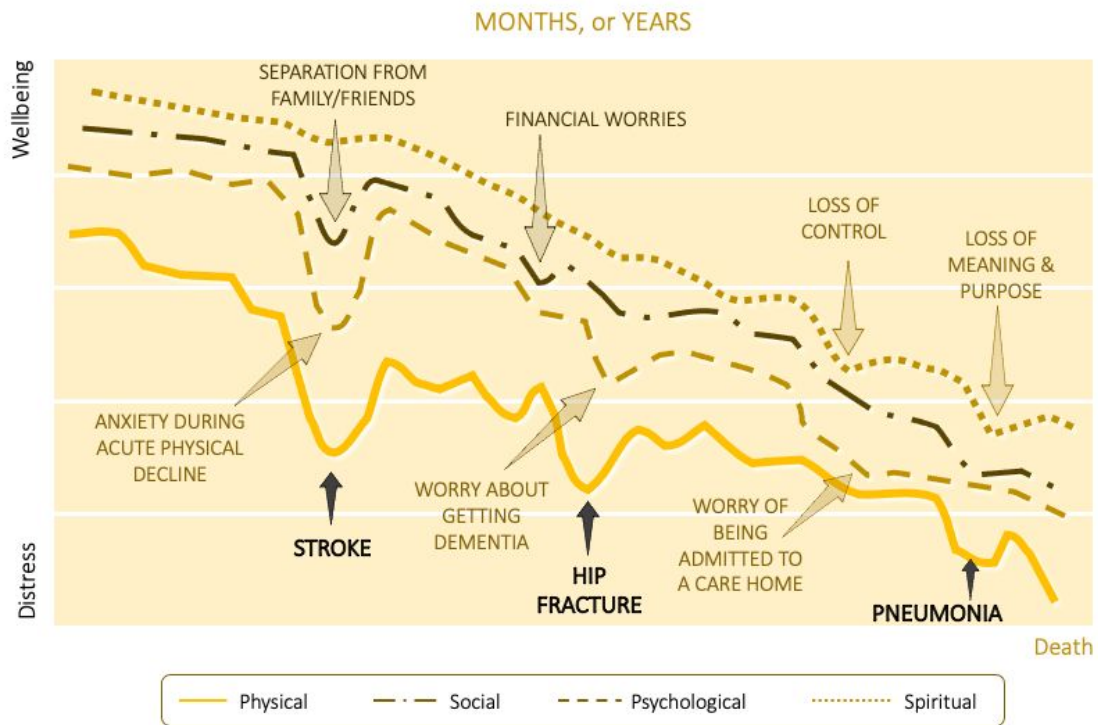


Figure 2. Wellbeing dimensions in people with MULTIMORBIDITY
(Two or more diseases in the same person at the same time)



Review Only

Figure 3. Four key steps in a dynamic cycle of multidimensional assessment and holistic care planning

