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Thinking Ahead: Exploring and Understanding Experiences and Decisions in End of Life Care

Stories about what matters to people at the end of life

Barriers and enablers in end-of-life care planning with people and their families from ethnically diverse backgrounds

A guide for learning for health and care professionals

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In collaboration with Andy Barrett for excavate
community • theatre • events

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The people depicted in each story are fictional but the experiences described have all been experienced by someone in our research. We are extremely grateful to those who gave us their precious time and provided a glimpse into this time in their lives.

The stories were written and produced by Andy Barrett for Excavate www.excavate.org.uk. They were read by: Sokari Erekosima (Sharmarke); Jim Findley (Dave); Gurpreet Grewal-Santini (Hafsa); Violet Hais (Emilija); Mufaro Makubika (Tawanda); Irfhan Ali Mururajani (Krushan); Dipti Patel (Balwinder); Ling Peng (Lanfen). Some were volunteers and we are especially indebted to them for their generosity and commitment to this work.

Contents

Introduction

This learning guide, the eight stories and an e-learning module support blended learning for health and care professionals about the things that matter to people who are in the last year of their life. Each story is derived from a range of experiences that have been related to us by real people and their families in the *Thinking Ahead* research [NIHR HS&DR 17/05/30]. The stories are fictional accounts of situations in which people with advanced illness and their families have at some time found themselves. The intention is to provoke reflective learning upon how health and care professionals might respond to the challenges presented in these stories with a view to fostering good practice and good outcomes for all concerned.

The *Thinking Ahead* research explored how terminally ill people from ethnically diverse backgrounds and their family think ahead about deterioration and dying and engage with professionals to optimise their care. The study sought to understand more about the nature of people’s preferences for end-of-life care planning and how current policy and practice 'fits' with diverse cultural values. There has been little previous exploration about the experiences of ethnically diverse people with advanced illness and their families in relation to their thinking ahead about deteriorating health and end-of-life and in their approach to planning for this.

As a result of the research we now know much more about these matters. In order to share these experiences with those professionals on the front-line of care delivery (particularly at end-of-life), these stories recount examples of the types of considerations that impact on people. These may be matters such as how care is organised within the family, how decisions are taken and by whom, whether people hold beliefs and values that determine the care that they would prefer and whether there are aspects of their lives that really matter to them and are important to their well-being. We suggest that effective support may be best enabled when professionals engage with these matters and get to ‘know’ each person; identifying where possible the things that matter to them and personalising end-of-life care to their priorities and preferences as far as is possible.

The learning resources

This learning guide aims to provide background information and materials that will support self-directed and group learning. The main learner audience is likely to be professionals who discuss prognosis and decisions about treatment and care with people. However, many of the stories will be useful for staff who support people at other levels.

Whilst the focus of learning is the context of offering discussions about future deterioration and dying the resources will be useful for broader discussions and learning about ethnicity, diversity and inclusion in palliative and end-of-life care.

The learning resources are:

- **Guide for learning.** This document! This can be used to aid self-directed reflective learning or provide support to learning facilitators who are delivering group events.
  The guide presents eight stories in the third person, identifies the themes and concerns that form part of the person's narrative and provides some suggested points for discussion. The key aspects of these stories are summarised in Table 1. These stories are also available in the first person audio format (see details below).

- **e-learning** Engaging effectively about advance care planning with people from ethnically diverse backgrounds https://portal.e-lfh.org.uk/Component/Details/746405

This session aims to build professional confidence and expertise in supporting people from ethnically diverse backgrounds to engage in thinking ahead about deterioration and dying at a time and at a level with which the person feels comfortable.

The session presents the key findings of the *Thinking Ahead* study and concepts and models that are important in developing culturally safe and personalised care including:

  - The iceberg model of culture
  - Sawubona: Being known
  - Authentic curiosity as a key skill
  - Cultural humility as an attitudinal imperative

The e-learning is available through free registration (https://portal.e-lfh.org.uk/) to all health and care staff including hospice and care home employees in the UK. The session may be purchased for use outside of the UK (contact eLfH)

- **Audio Stories**: Long and short audio versions of eight stories, powerfully told in the first person. They are available here: https://loros.co.uk/research-at-loros/thinking-ahead/thinking-ahead-stories

  The long story is around five minutes and the abridged version around two minutes.

- **Transcripts** of the eight long and eight short audio stories are available here:

  https://loros.co.uk/research-at-loros/thinking-ahead/thinking-ahead-stories

Abbreviations we have used in the resources

We have tried to avoid abbreviations but some phrases are used so repeatedly that we think abbreviation is useful.

HCP	Health Care Professional
EOLC	End of Life Care
EOLCP	End of Life Care Planning
DNACPR	Do not attempt cardio-pulmonary resuscitation

Other resources

A useful resource to increase your knowledge about the diverse faiths that people may hold is *Spiritual Care: A multi-faith resource for healthcare staff. NHS Education for Scotland 2021* https://learn.nes.nhs.scot/50422/person-centred-care-zone/spiritual-care-and-healthcare-chaplaincy/resources/multi-faith-resource-for-healthcare-staff

Feedback

We would love to hear about how you have used them, what the impact has been and any ways that you would suggest to improve them. Please do send us your evaluation and comments (see appendix 1).

A summary of the findings of the *Thinking Ahead* research

The predominant stance of people with advanced, terminal illness in our study was to live with hope. Their considerations about the future were mostly limited to practical matters (wills and funerals) rather than thinking about what may happen to them physically and about dying. Planning ahead about decisions they may need to make about care and treatment was not seen as important by most people and for some people was not in line with their values and/or their faith. However, we also found that a consequence of the absence of such discussions and the family's lack of awareness sometimes lead to deterioration and death being unexpected. This, for some but not all, was a devastating experience, followed by regret that they had been denied the chance to prepare.

Our findings indicate that what constitutes a good end-of-life is influenced by a number of factors including, but not limited to, those of beliefs and culture. Religious and cultural customs were of great importance to many people and there were anxieties about how the health and care services valued and enabled these to be practiced. This was not always the case however, and it was not possible to predict the nature and strength of religious commitment from ethnic affiliation. People's perspectives and responses were very diverse, and individuals did not want to be typecast by professionals on the basis of simplistic assumptions based on their ethnicity. Family duty and community expectations were very influential in some people’s lives as was concern about being looked after by strangers who didn’t care or understand their values and needs was common.

Some participants indicated a lack of trust in professionals and many had experienced a disjointed health system. To many this made them feel that they were not offered due regard and this undermined their sense of dignity and wellbeing. All people desire personalised, compassionate and holistic end-of-life care. This approach holds true for people from minority backgrounds as well as the majority. We do not need a different framework to guide us in how to support people. However, it is the nuanced and personalised delivery of care in this framework that is crucial. People need us to focus on equity in <u>outcomes</u> (not inputs or processes) such as excellence in our communication with people where there is a language barrier and the way wellbeing is supported for those where spiritual/religious requirements are a dominant factor in their lives. The additional range of skills and resources that are required to achieve these aspects of care is one of the challenges for professionals and services. The research highlighted the need for development of professionals’ skills in supporting people where the ‘usual’ way of doing things is not adequate to achieve good outcomes for what a person needs.

Some key things that people told us in the *Thinking Ahead* research

> **…. to be culturally sensitive, to be sensitive to her background, her religion. I guess just checking with the family to see if it’s OK…if they do want to do something, is it OK. To be aware of her dietary needs, her modesty. To be aware of her scripture needs.**

> **Some days when it’s a particular religious occasion, I might want to see the temple or something. Then the carers just man-handle me…as they feel like it…it immediately infringes on whether I can then go to the temple or not because I feel I am unclean.**

> **This is the first time that we were experiencing end of life and palliative care and …. she [palliative care nurse] was quite aware of that…. she was just very available like giving us some advice…. And she was very warm, very open. And she gave us a lot of information as to what to expect next.**

> **I would sum it up… it’s a battle**

> **They don't have time to really look at you as a person properly…**

> **I think they [GPs] just had a lot of empathy. It makes a lot of difference when they are empathetic and they realise what the patient is going through, where they are at and the family where they are at.**

> **So they really need to look at the notes find the information. Have a small group of people that know about me and know about your circumstances; know about what treatment we can give you and what the outcome could be.**

> **But what we have found is that the health profession does not understand and are not able to understand that there are real differences in how to approach, our care and our needs. That is a key thing. And how does one begin, where does one begin with that?**

How stories can help us learn and change our practice

There is evidence to suggest that sharing key messages through stories has a greater potential than other methodologies for changing attitudes and having an impact on behaviours. A story is not just a series of words and sentences. It makes us think and feel and may open our minds. It can help us see things from different viewpoints and stories can change us. Stories are often used with the public as interventions to influence health behaviours. Stories used in training have been shown to enhance and sustain the development of empathic practice of clinicians.

Research in the ability of stories to transport their audience and thereby open them to new ideas and different ways of thinking and acting suggests that empathy with characters, identification with characters and vivid imagery change the usual way of thinking and acting of the person ‘hearing’ it.

We have developed stories based on the experiences of the 103 interviews with people in the *Thinking Ahead* research. The stories have evolved and developed, informed extensively by comments from lay and professional stakeholders involved in the project and from their use in conference talks and teaching.

We worked with a professional writer/story teller and producer to develop the stories which were performed by four professional actors and four volunteers in the audio recordings. The stories have been designed to reflect a diversity of demographic characteristics and contexts and to focus on specific themes arising in our data and are described in Table 1.

Table 1: The context of the eight stories about what matters at the end of life

Story	Sex	Age	Ethnicity Faith	Main location	Illness	Key themes
Sharmarke [Son]	M	25	African Muslim	Hospital	Unspoken	Complex life circumstances of migrants: what lies beneath the surface/behaviours. Duty. Misunderstandings. Taboos and fears. Knowing the systems.
Balwinder [Daughter]	F	60	Indian Sikh	Hospital	Unspoken	Carers duty and burdens. Language/communication barriers and burdens on family. DNACPR.
Dave	M	70	African Caribbean Agnostic	Home	Cancer	Lack of trust. Misunderstandings. Rights. The need to battle.
Emilija	F	80	Latvian Catholic	Hospice	Unspoken	Offering the opportunity to discuss deterioration and dying at a time of readiness. Aligning care to priorities of patient.
Hafsa	F	80	Pakistani Muslim	Home	Heart disease	Autonomy and decision-making complexities of family culture. Knowing the patient. Communication. Importance of faith and religious practices.
Krushan	M	59	Indian Hindu	Home	Unspoken	Pressures of community and family judgement. Planning ahead and accepting care.
Lanfen	F	65	Chinese Buddhist	Hospice	Diabetes / kidney failure	Being seen/known: Don't make assumptions about heritage and actions/preferences. EOLC is journey of accompaniment of the lead player.
Tawande	M	38	African Christian	Home	Cancer	Ambivalence in discussing/relevance of planning to life approach. Faith- God's will not mine. Sustaining hope/ collusion. Community pressure. Team endeavour.

Knowing the person and their family

Each of the stories in this document identifies a range of concerns and dilemmas drawn from interviews with people living with advanced illness, their family and health professionals that support them. They point to a whole range of matters that it would be good to establish about the person and their family, in order to develop shared understandings of their preferences and to support them effectively.

Each person will have their own set of unique characteristics, hopes, fears, and knowledge when they engage in the healthcare system. Each will be at a particular place in their illness journey and may have distinct preferences for care and possibly a need for differing ways in which these matters might be communicated (for example, using a translator or a designated family member). They may or may not understand or wish to be fully informed about their prognosis and may trust one or two key professionals to talk with about this. Furthermore, they bring with them both a health and a personal history and will have varying knowledge and may have had very diverse experiences of engaging with the health and care systems and other institutions in the UK and in other countries. These experiences will impact on trust in formal health care and access to trusted relationships with individual professionals. They may also have very distinct cultural and spiritual values and principles that influence the way they navigate their illness and any treatments. They may have strong connections to an informal advisory infrastructure such as faith leaders or community advisors.

All of these matters may impact the way they and their family organise care for the person and what ‘outside’ and/or professional support they may seek or even resist. These matters will impact the choices they make and the way in which decisions are made among wider families or support networks; about treatment and ongoing care (including end-of-life care). Each family will work differently in terms of the way they communicate and in terms of their family dynamics. People are unique and have a diversity of perceptions about whether discussing end-of-life is relevant to them and if/when this might seem appropriate. What is important is that we personalise our interactions and support for people. These resources aim to support development of this where the professional feels uncertain as to how to do this and as a consequence, unhelpful assumptions can then be easy to make.

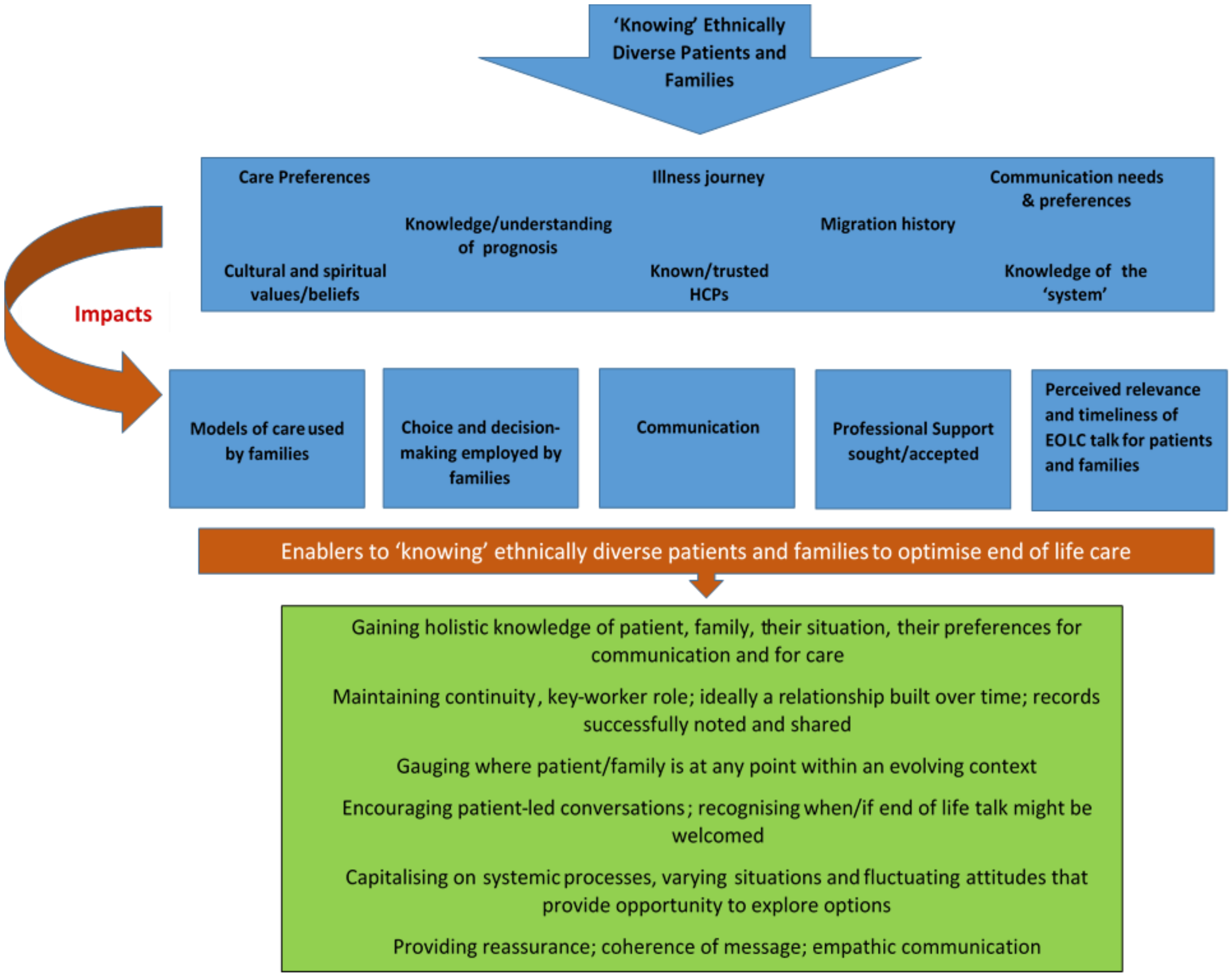
There are many factors to be considered about each family and it is acknowledged that often acute health crises mean that at the point of care it is impossible to glean everything about a person and family in a short time. However, if some of these matters are known and noted already this will help enormously, especially when this information has been gleaned over time. A relationship built over time which has enabled discussions about end-of-life might avoid the sometimes “harsh” communication in urgent care scenarios, reported by some of the people and families in our study.

Some key skills, relate to being able to gauge ‘where’ people/families are in an evolving and uncertain time; in taking opportunities that may arise to broach end-of-life matters and sensing when these may be welcomed. A key message that came from our research participants was the importance of compassion and empathy that was present in some professionals’ communication whether during an acute episode of illness or in dialogue over an extended period of time.

Feeling ‘known’ and being ‘seen’ with due regard and respect mattered greatly to those we interviewed as it engendered a trust that ultimately enabled sensitive and often difficult matters about end-of-life preferences to be broached in a relevant and timely manner. We have used the Zulu greeting Sawubona [I see you] to encapsulate this. It echoes too the understanding of dignity preserving palliative care which has been developed by Harvey Max Chichinov.

These points are summarised Figure 1 below.

Figure 1. A framework to support people from diverse ethnic backgrounds to feel ‘known’



Gaining holistic knowledge of patient, family, their situation, their preferences for communication and for care

Maintaining continuity, key-worker role; ideally a relationship built over time; records successfully noted and shared

Gauging where patient/family is at any point within an evolving context

Encouraging patient-led conversations; recognising when/if end of life talk might be welcomed

Capitalising on systemic processes, varying situations and fluctuating attitudes that provide opportunity to explore options

Providing reassurance; coherence of message; empathic communication

Sharmarke

Sharmarke, a young Somalian man, is waiting at a bus stop to visit his father at the hospital. He has a phone and headphones that somebody from the Somalian community centre has given him to take to his father, with whom Sharmarke arrived here in the U.K. under two years ago. It has been a very difficult time. After only a few months his father became seriously ill and has since been in and out of hospital. Sharmarke has found it very difficult to support his father during this time, whilst also working (illegally), manage their rented accommodation and deal with their claim for asylum status. He has also been learning English and it has taken him some time to be able to understand what the doctors were saying to him with translation sometimes being unavailable. One of the nurses at the hospital suggested that Sharmarke visit the Somalian community centre who may be able to help and as a result there were times when Sharmarke was able to bring someone to help translate. Whilst he was worried about his father, he was also relieved and happy that he was being cared for.

Over the last two months his father has taken a turn for the worse and has been back in hospital again. Sharmarke, working very long hours for little pay, is really struggling and has felt increasingly guilty about not being at his father's bedside as he should be, and there have been moments when he has arrived to discover that his father has been unable to ask for help with going to the toilet when needed or being given food that wasn't suitable. His father seems distressed and confused, uncertain of what is wrong with him, even though the doctors have been trying to explain, and Sharmarke is finding the experience increasingly stressful. Not only is he worried about what will happen to his father, he also – although he will not mention this to anyone as it will only tempt fate – has no idea of what to do if his father does die. What will happen to the body? How will he bury him in the right way? How much money will he need for this to happen?

One day Sharmarke snapped. At the hospital after a difficult day at work, and still waiting to hear news of his immigration status, a doctor started to talk to him about any plans he and his father might want to put into place for his father's death. Sharmarke did not understand why they were talking to him about this, about his father's funeral. When the doctor tried to explain that this was not what he meant, that they needed to consider what might happen if his father became so unwell that he might die, Sharmarke became increasingly agitated; thinking that his father was about to die, that the doctors were giving-up on him; that they wanted to use the bed for somebody else. Sharmarke became very emotional, trying to explain that it was his duty to keep him alive; that it was not their place to talk about death because that is in the hands of God; that it was their job to find a way to help him. That it was clear that, just like the Government, they did not want his father or him here and that they should never have come to the UK; that there was nobody here to help him. Having stormed out of the hospital Sharmarke became very worried about the implications of his behaviour, that he would be reported to the authorities for being so aggressive and did not return for several days. He was also convinced that when he did return his father would be dead and was full of shame and remorse for his actions. He should have been praying more; he should have gone to the mosque to seek spiritual help for his father; but he has been worried about losing his job as he has needed the money to pay for his visits to the hospital and the things his father has needed.

Going back to the community centre he tried to find someone who could explain what was happening and what the doctors meant, but although he was offered sympathy there was nobody there who was able to clearly explain the situation to Sharmarke and their conversation, again, turned to the funeral rites that may be involved. Although this was not what he wanted to hear it did, at least, offer some solace that he would be supported by the community when that moment came. And somebody also offered to come to the hospital with him the next day to see if they could find out more information from the doctor and to smooth things over between the hospital and Sharmarke.

Dressing himself up to look as smart as possible Sharmarke returned to the hospital and was overjoyed to find his father still alive, although still very ill. Whilst sitting at his father’s bedside a sympathetic male nurse had come up to say hello to the man who had accompanied Sharmarke and, after hearing about what had happened, had spent some time with him to explain the situation and what the doctor had been trying to ask him.

This has calmed Sharmarke a little, although he was also very surprised that people would talk about such things. Today he is going to talk to the doctor, with the support of the nurse, so that they can explore the possibilities for his father’s care in what Sharmarke is coming to accept may be the end part of his father’s life. He will give him the phone, which has verses from the Qur’an on that his father has not been able to listen to whilst in hospital, and then the conversation with the doctor can take place. It will not be easy but perhaps it will be the start of some decisions finally being made. And maybe when he gets home, he will have finally received a letter from the Home Office.

Themes and concerns

Language and translation challenges are evident, as are challenges in understanding medical terminology and what EOLCP might entail.

A chaotic and uncertain domestic situation prevails for Sharmarke. He works hard and is often tired.

He has a limited support network, though there is little community knowledge about EOLCP to assist him.

His limited experience of the healthcare system has not all been positive. He feels some mistrust.

He has a strong Muslim faith and belief in God and the duty required of him as a son.

Points for Discussion

What do you think matters to Sharmake? And how might you explore this?

What could be done better to enable identification of what is important to his Father?

What could the HCPs have done differently?

What would be useful for HCPs to know to help them support Sharmarke and his Father?

What questions might they ask to explore this?

How might trust be rebuilt?

How might you increase your understanding about the Islamic faith, Qur'an and its place in people's life?

Balwinder

Balwinder is getting ready with her husband and her sons to go to the hospital to see her mother, Surinda, and to celebrate Vaisakhi, the Sikh New Year festival. There they will meet her younger sister Gurpreet and her husband, and her younger brother Ajeet and his wife who have flown over from Germany where they live. Gurpreet is providing the food and will, Balwinder is sure, take in too much as usual (she is convinced that the hospital food is unsuitable and that Surinda is not eating properly). Gurpreet and Balwinder have become very popular visitors on the ward as a result of this surplus of food which usually ends up being shared out to those in nearby beds. In fact, when Balwinder appears on her own there seems to be some disappointment at her sister's absence.

Balwinder knows that she should be putting on a brave face and trying to enjoy the day, but she is very anxious. Her mother has been increasingly unwell over the last three weeks and it has fallen on Balwinder to act as the translator between the doctor and her mother who does not speak English well enough to understand what she is being told. Although the doctor has offered Surinda the use of a translator she has refused, saying that her children will let her know what is being said. This has fallen on Balwinder as Gurpeet has made it clear that she gets too emotional and cannot remember what is being said (which is why Balwinder thinks she cooks so much food, to compensate for her guilt at leaving this role to Balwinder). Although Ajeet comes over as much as he can (even though Surinda keeps telling her daughters that they are not to bother him as he is very busy) and all family decisions are made after talking to him on the phone, they have agreed that it is best to have one person acting as communicator between the doctors and their mother.

The doctors have been pressing Balwinder to make a decision about whether or not a DNACPR order should be put in place because Surinda's health has been failing, alongside other end-of-life care decisions. When first asked about this Balwinder was too upset to communicate it to her mother and feeling in something of a compromising position ended up telling the doctor that she had explained everything as asked and that her mother had replied that she needed some time to discuss it with her children, even though this was not the case.

Balwinder has been surprised at the kind of questions that her mother had been asked to reflect on, having never really considered the idea of end-of-life options and decisions. She feels annoyed that this discussion has not happened sooner and wonders why their family doctor, who they have been going to throughout their lives, has never brought these questions up before, instead always saying that their mother was in good hands and that everything would be alright; that they should try not to worry. Is he just leaving this difficult conversation to the hospital doctors because of his close relationship to the family? Or is it possible that the doctor has had a conversation with Ajeet who has hidden this from his sisters just as she has hidden her conversation from her mother?

Balwinder has never been completely happy about their relationship with the family doctor yet when she had suggested that perhaps the family could ask another doctor to see their mother, who might be able to be a little clearer with them about the situation, this idea was dismissed by her brother and sister who thought that what was most important was that their mother felt comfortable seeing somebody that she knew, someone who was almost like a family friend.

As a result of all of this Balwinder is feeling anxious, aware that she has been untruthful to both her mother and the hospital doctor and wants to rectify this as soon as she can, so that she can engage with this awful situation and everyone involved in it in an open and honest way during these difficult days. But her siblings have told Balwinder that they do not want her mother to be worried about such things. That this will only confuse her and make her weaker still; that she will not understand them; that they must not detract from the upcoming celebration; and that they are not prepared to sign her 'death warrant'.

Feeling as though she is being pulled in many different directions, Balwinder has spoken to a close friend who has told her that they must talk about these questions as soon as they can and that it is important that they should not be put off.

Balwinder is dressing up to look her best on this auspicious day. They were planning to celebrate at home, but this cannot happen now; and Balwinder is slightly anxious about what will await them in the hospital and how much of a celebration the family will be able to have in such a public situation. Of course, with all the food that Gurpreet will bring it will end up being a ward party. And although the family still harbour hopes of their mother returning to the house (this house, where Balwinder and her husband live) they are worried about how she would cope with the steep steps up to the front door, let alone all of the other challenges of navigating around the small rooms. The house just doesn't seem suitable anymore and although she has heard there are ways in which they may be able to get financial support for adaptations it all seems very difficult. Their brother is insistent that the hospital is not suitable because at times there are male nurses who help with their mother's care, and during an early visit she was asked if she wanted a halal dinner. When Balwinder has been alone with her mother and has asked about these issues she has said that everyone in the hospital is very nice and helpful.

Balwinder has decided that tomorrow, after they have celebrated, she will sit down with her brother and sister to talk things through in as much detail as possible. She can see that as her mother's health is deteriorating the family may need to make difficult decisions on her behalf. She will write it all down so that there can be no mistakes. This is how she can enjoy the day, knowing that tomorrow all of this pressure she is feeling can be shared out. And she is glad her sister makes so much food. It is a family trait and if they can't bring her mother home to the house at least they can try to bring some of her life into the hospital.

Themes and Concerns

The topic of DNACPR is upsetting and shocking for Balwinder.

She is somewhat isolated in thinking it all through.

Language is problematic and this adds to Balwinder's feelings of pressure as translator and advocate.

Her siblings' desire to keep information from their Mum leaves Balwinder feeling dishonest and pulled in varying directions.

There are ongoing concerns around food and personal care for Surinda.

Balwinder feels under constant strain as a carer, though she would love to get her Mum home.

Points for Discussion

What do you think matters to Balwinder? And how might you explore this?

What would it be useful for HCPs to know to help them support Surinda and her family? What questions might they ask?

How might HCPs capture more of Surinda's 'voice'?

How could the discussion about DNACPR have been done differently with Balwinder?

What key questions would have been helpful to ask Balwinder in order to support more effective discussion about DNACPR?

If you were providing care for Surinda consider how you could contribute to the care plan?

Dave

Dave is waiting for his friend Biant to take him to the hospital as his wife cannot drive and he can no longer afford the insurance on his car. He has an appointment with the doctor who has asked him during his last appointment to think seriously about what he may want to happen over the next weeks and months. Three months ago Dave finished a course of chemotherapy which has not had the desired effects.

Biant and Dave are old work colleagues. Biant has been very supportive and has suggested that Dave get in touch with a cancer charity about a group where they can go to play dominoes and chat. But Dave is wary. His brother's wife has been trying to convince Dave that he should never have had the chemotherapy and that he should follow a specific diet and start eating certain types of food. Dave thinks that this is nonsense, but as his wife has always done the cooking and thinks that there must be some truth in it and that there is no harm in trying, he has found himself eating this new food.

He doesn't enjoy it; it seems very expensive; yet he has been advised by Biant – and he knows that he is right – to do what his wife suggests and to keep her happy; even as both Biant and Dave rail against some of the ridiculous ideas that people have about death in their communities. The bottom line is that death comes, and you just go and you leave the mess behind. He can still vividly remember going to Portmore with his parents as a child as his grandfather was dying and seeing the dead body. That is the way death should be. Not hidden away and talked about quietly but just a part of life. If it was down to him and Biant you'd be able to do away with yourself when you felt the moment was right rather than carry on like a wounded animal. And don't get him started on British funerals.

Dave knows that he is very ill, but he is not stupid and is not going to sign anything that means that the doctors can wash their hands of him now that the treatment hasn't worked. For weeks afterwards they didn't want to know about him, and he has had to deal with the consequences of incontinence and impotence on his own. Everyone knows that just like everything else, things are stacked against people like him. (There was that bloke with a prosthetic arm in the darts team who always wore long sleeves in summer because they'd not been able to give him a black one. Typical!).

Now that they think he's going to die they obviously want him to sign something that means that they can cover their backs. Well they're not going to get rid of him that easily.

At the end of the day the only one that he really trusts is his old mate Biant. When you've spent days on the riverbank with someone putting the world to rights then you know who your friends are. On one side he's got his wife's family trying to push their mumbo jumbo cures on him; and on the other a health service that is looking for ways to save more money and to cover their backs

Themes and concerns

Dave has a lack of trust in the healthcare system, linked to some misunderstandings, particularly about legal aspects of EOLCP.

Dave has found himself in a strange (in limbo) position, between needing cancer care and not yet needing palliative care. He feels he is being 'written off'.

Cultural 'fads' around diet are negatively impacting his sense of well-being. Loyalty to his wife means he continues with this.

A societal reluctance to talk about death and dying compounds his isolation.

He has identified potential support that charities can offer.

Previous experiences of death and funerals are influencing his perspectives now.

Points for Discussion

What do you think matters to Dave? And how might you explore this?

How might you explain the following words or phrases in a conversation with Dave:

Advance care planning

Palliative care

DNACPR

How could Dave's misunderstandings have been identified? What questions could you ask to help facilitate this?

Can you think of examples from your own practice when death has not been talked about openly?

Based on Dave being your patient, carefully consider your own role in his care and how you would contribute to the care plan.

Is there any important information that is not apparent in this story? What questions or discussions would you have with Dave and his wife to explore any missing elements to ensure the care plan is complete and personalised?

What could be done to support his wife?

Emilija

It is Holy Saturday and Emilija is waiting for her daughter to arrive at the hospice for them to spend the day painting margučiai*. She has asked some friends to join her and a table has been set up for them; and she is hoping that her daughter won't mind the extra company. But painting the Easter eggs is such fun, and she and her daughter have always made such a good job of it (having only ever missed one year doing this together), and she wants to share this with others. After all she has to put up with everyone else's traditions.

Emilija is also aware that this will, in all likelihood, be the last time that she and her daughter get to do this together. Although she knows that her daughter is still hoping that her mother will recover; that a cure may be found for her, Emilija is at peace. She is being well looked after. People help her wash and dress and go to the bathroom and sometimes eat. It's not what she wants, but it's the way it is. She has prepared everything for her death; written it all down which has given her piece of mind. And she knows that if things take a turn for the worst that she has told the doctors what they can and cannot do.

That was a difficult day and her daughter seemed to disagree, but Emilija stood her ground. The Doctor seemed to know that this was the right time for the conversation, that she had waited until she was a little stronger after having had an operation, and perhaps sensing that Emilija was ready, as she was, to talk about end-of-life matters, particularly DNACPR. And she had led it well; gently and calmly and asking how she could be of most help in supporting Emilija and what Emilija cared about. (It was then that she had thought of how much she cared about painting eggs with her daughter.) The Doctor also spoke kindly to her daughter afterwards to console her and to explain what Emilija's decision meant and how it would only ever be used if the doctors were absolutely convinced that it was for the best.

Emilija is thankful to the Doctor and to the situation she is in which is so very different to that of the time of her husband's death. That was a terrible experience. First there was the delayed diagnosis, then when he was taken to hospital, where he ended up dying. There was nobody who ever really explained properly what was happening and she found herself being inundated with questions that she didn't really understand and everyone seeming so rushed all the time. Worst of all was the lack of privacy and space to grieve. Emilija made a promise to herself that this must not happen to her daughter; for her to see her mother dying like she had seen her father dying. That was the one year when they missed painting margučiai.

It was during her husband's illness that she had started going to the Lithuanian church again, even though she is not, and has never been, a particularly religious person. It has remained a constant in her life since, and she has found pleasure in reconnecting with a cultural heritage that she had started to move away from. Apart from the Easter traditions of course; you never forget those. Some of the friends she made at the church come and visit and the one thing she regrets is that she won't be able to return to Lithuania to see the hometown that she moved away from when she was a little girl. Her friends always tell her that everyone is praying for her, and that there is still hope that she will return, and although she doesn't really believe this, she finds comfort in their belief. Between the doctors and God she seems to be in very good hands, which is why she never wants to make a fuss if things aren't ever quite right. She should be thankful for what she has now. If only her daughter could see that. If only she would stop feeling so guilty about not having her mother at home.

Emilija hopes her hands don't shake too much today as she'd like to do a really good job with her eggs. To show her daughter that she is well; and to show off her culture to those that are joining in with them. She's already decided that she's not going to wash her hands when it's all over, and must remember to tell the carers, because she always remembers how fascinated she was by the way the tips of her fingers changed colour when she painted margučiai with her mother.

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* margučiai: The decoration of eggs, a traditional celebration at Easter time in Slavic nations.

Themes and Concerns

Emilija has learned from previous experience (some of it poor) during her husband's illness.

She sees security in having a plan in place.

She is keen to protect her daughter from any feelings of guilt and minimise her distress.

Emilija highlights the importance of the quality of HCP's communication.

She defers to HCPs to know what is/will be right and when.

Cultural rituals are important to her in maintaining a sense of herself and social integrity.

She draws some support from her faith and being in this community.

Points for Discussion

What do you think matters to Emilija? And how might you explore this?

Based on Emilija being your patient, carefully consider your own role in her care and how you would contribute to the care plan.

Consider the roles of other professional's and how they would also contribute in supporting Emilija and her daughter.

Reflect upon Emilija's two differing experiences of talking with HCPs about her and her husband's illnesses. What can be learned?

Hafsa

Hafsa is very ill, having had a history of heart problems and of various surgical interventions. Over the last months her health has declined and having recently had a stroke she is finding it very difficult to communicate. She is being cared for at home by her family and is aware that she is in the last stages of her life; something that she has accepted.

Later today Doctor Lakhani, her GP, is due to visit. Although she had told Hafsa on her very first visit to call her by her first name, Indrani, Hafsa has never felt that this is right and has always called her by her proper name, Doctor. She has worked hard for this and should have this respect bestowed upon her. Hafsa is looking forward to this visit although she knows she will be frustrated at not being able to talk to the Doctor like she used to. The first time Doctor Lakhani came to the house most of the time seemed to be spent talking about the family photographs on the wall, which was not what Hafsa was expecting but was just what she needed. She has found their conversations comforting and interesting; getting to know someone a little right at the end of your life reminds you how interesting every day can be and how there is always something new to learn. And there is something of the Doctor that reminds her a little of herself when she was younger.

Hafsa is not afraid of dying; she feels she has had a good life. She has talked to her family about her wishes for the end of her life but was not planning to share these with the Doctor, because these are family matters. Yet when Doctor Lakhani started to talk to her about such things Hafsa found herself unexpectedly telling her everything that she was feeling and thinking. It is a skill, for sure, this talking business and the Doctor has it. She also makes sure that any conversations where she wants to ask questions that will impact on the family happen by her bedside and she always keeps looking at Hafsa throughout these encounters, especially since the stroke. It feels a little strange, as though the Doctor is trying to put herself into Hafsa’s shoes. Yet Hafsa can see that her children are waiting until they leave the room with the Doctor before they ask the questions that they really want to.

Hafsa is being cared for at home by her family and they are doing a wonderful job. She couldn’t ask for anything more. They have moved her bed so that she can look towards Mecca, even though the view isn't as good in this new position. They help her perform her ablutions and recite Ya Seen Surah* to her now that she cannot speak the words of the Shahadah**.

She had suggested to her children that they think about taking up the assistance with home care that the Doctor had offered. But this seemed to upset her son, who is a very devout man and studying to be a Hafiz***. He argued that Allah will turn his face from those who do not care for their dying parents and that it would be impossible for carers to fit their schedule around prayers. Her daughter agreed, also saying that she has worked out how to cut up her mother's food so that she can swallow it easily, how to put her in her favourite position, how to move her gently, which clothes go with which. Hafsa understood but as time has gone on she can see that her children sometimes look tired from their caring duties. Before her stroke she did bring it up again with her daughter but no carers have arrived and so it seems as though the children have decided against this.

It's a pity because much of the time they are with her it is as though she is their patient rather than their mother and she sometimes wishes that they could just sit with her and be themselves, like Doctor Lakhani seems to. But of course if this is what the family has agreed then that is as it should be. Last night the Imam came round, and he and her children had a long conversation about something, but that didn't take place by her bedside and so she doesn't know what they were discussing. She thinks she heard the word resuscitation but can't be sure. They were probably arranging what happens when she does pass away, because it cannot be long now. Last week there had been a long discussion, well actually more like an argument, when the Doctor said that she could arrange for drugs to be brought to the house in case things became difficult for her. Hafsa is hoping that these will come soon because if the Doctor has advised it, it is probably a good idea. Yet she knows her son was not happy with the idea.

What she hopes more than anything is that her children are thankful to Doctor Lakhani when all this is over, and that perhaps they may still keep in touch with her. But of course this probably won't happen; she must be a very busy woman and there are so many people who must need her help. Maybe she can ask them to take a photograph of the two of them together today; the Doctor and herself. There must be a way she can make them understand.

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* Ya Seen Surah: Surah Yaseen is a chapter in Qur'an which has particular purposes. Amongst these is that is seeks forgiveness from Allah, and at that death will be peaceful and pain eased. It is also said after someone has died to seek forgiveness from Allah.

** Shahadah: This is the declaration of faith of fundamental importance for Muslims. "*I bear witness that there is no God but Allah and that Mohammed is his final messenger*." It is something which is pleasing to God and felt to be very important to say or hear at the time of illness and dying. It is something that might even be said by a resuscitation team for a Muslim patient who dies and can be of great comfort to their family to know this.

*** A Hafiz is someone who has memorised the Quar'an and has a position of respect in the community because of this knowledge and wisdom.

Themes and concerns

Although Hafsa has a sense of what she wants, she defers to her family for decision-making.

The family have strong preference and sense of duty, based in their religion, towards looking after her themselves.

The family see Islamic prayer and practices as fundamental to Hafsa's wellbeing and care

Hafsa has a strong, positive relationship with Dr Lakhani, built around person-centred conversations.

There are family tensions about some issues (e.g. provision of care and 'just-in-case' medicines)

The family are keen to seek/adhere to religious guidance about aspects of care; in particular DNACPR.

Points for Discussion

What do you think matters to Hafsa? And how might you explore this?

Hafsa felt Dr Lakhani had good communication skills -what was it that she did that was helpful?

Can you think of examples from your own practice where you thought end-of-life discussions went well and what was it that you thought was helpful?

How might her family be supported?

How might further discussions about just-in-case medications and resuscitation be taken forward?

Krushan

Krushan is in bed at home waiting for his brother Abhijeet to arrive from Mumbai. His wife has been working flat out to make the house tidy. Krushan is not looking forward to meeting Abhijeet because he knows that he is going to boast about his business success and that he will – as he always does – make it clear that every decision Krushan has made is the wrong one. He also knows that if other visitors come – there have been a lot lately – that his brother will want to boast to them as well.

Krushan has decided now, to engage wholeheartedly with the support that is on offer to him, especially now that he has decided that on no account does he want to spend his last days on this earth in a hospital with strangers. He has always been told that he should stand on his own two feet, something his brother has continually espoused as at the heart of his success, and it is, he reflects, partly as a final act of rebellion against his brother that he has said 'give me everything that I am entitled to'. And he is surprised at what is available and how much care is being provided. There are even people coming to his house to make some changes that will help him move around more easily; something that he wasn't expecting at all (and which he wishes he had known earlier). His wife however is still struggling with the presence of the carers and Krushan telling her to 'let them do the work; that is what they are being paid for', which has caused some tension.

He wishes he knew how to talk to her about what was happening to him; about death. But he doesn't wish to add to her concerns. She says that she will do whatever he asks of her; that it is up to him to decide how things should be. In fact, he wishes there was somebody he could talk to about how he feels and what he wants, because it has seemed that it was only when he began to ask for things that what was available became apparent. And although this help is wonderful, he is still worried about what happens when he gets close to the moment. Nobody has really told him that and he doesn't think his wife would ever ask such a question; so it is down to him to get these things all straight, although he's not quite sure how.

Krushan knows that Abhijeet will criticise his wife, and maybe even himself too if he doesn't look too ill when he arrives. He will think (and probably say) that the fact that his family are not shouldering all of his care is proof of his relative failure in life. That the carers will not look after him in the proper way so that he can go to the temple with peace of mind. That they do not understand Ayurvedic medicine which may be helpful to him. That his energies and forces are out of balance and that he needs to fight rather than submit. That it will show their family in a bad light amongst the local community. And of course Abhijeet will know someone who only had a week to live but is now playing in the slips for his local cricket team through sheer force of will.

But Krushan is pleased he decided to accept extra care. He can see that his wife is less tired and anxious. She has been struggling with all the different appointments and the many conversations that seemed to be taking place. He is pleased that his relationship with his daughter has changed; that he could see that it was sliding into a patient-carer relationship when he needs to use this time to pass on some wisdom, although he does not know what this wisdom might be.

He knows his wife is anxious about the relationship with his brother and they have been arguing about this. It is not easy. He doesn't want to upset his wife, and he knows that families have fallen out during these difficult moments, but he is not going to let his brother tell him and his family what they should be doing. In fact Krushan is hoping that the carer arrives at the exact moment when Abhijeet turns up. Because he is going to do exactly as he wants in these dying days. He may even go to the hospice and spend some time with strangers, as has recently been suggested to him. He reflects that it would be good if his brother would accompany him, whilst he is over here.

<u>Themes and concerns</u>

Pre-existing family tensions and sibling rivalries are influencing Krushan and his family's responses to current circumstances.

Some stresses seem to emanate from cultural expectations within a much wider community.

Krushan feels a number of benefits from accepting help form outside the family.

He would welcome opportunities to talk about his situation, and to express his acceptance of it, rather than his submission to it.

Concerns about ‘the right’ care and ‘the right’ medicine exist, though they may not be his key concerns.

Points for Discussion

What do you think matters to Krushan? And how might you explore this?

What could be done to support his wife and wider family?

What more would it be helpful for you to know to help you support Krushan and his family? What questions might you use to explore this?

How could HCPs approach some of the conflicts that exist for Krushan and maximise the opportunity to talk that he seeks?

Lanfen

Lanfen is getting ready to go to the hospice for the day, as she has been for the last three months. It was suggested to her by a doctor who could see that she was lonely, being a divorcee with no children. Lanfen did not like the idea, thinking that it would be like being in an old people's home, that she would be miserable and get in the way and that once she went through those doors, she would be trapped in a world that she wouldn't be able to leave. And one in which there would be nobody like her.

Lanfen is not, by her own admission, a sociable person. For a long time she refused to take up the offer of carers to come to her apartment because she did not want strangers coming in and telling her what to do in her own home and telling her off for her bad habits. Yet as time went on, and without help, she found herself being taken into hospital, often for situations that may have been avoided with care at home. Having finally agreed to have carers helping her she has made it plain to them that she knows that her lifestyle is not as healthy as it should be, given her situation, but that it is her life to do with as she wants and that they are not to say anything.

Anyway Lanfen does not trust doctors. She has told them not to tell her how long they think she has to live as they do not know what they are talking about. Her sister died not long after an operation that she was told might sustain her life, and everybody knows that the health system is a mess, and that the only way you ever get anything good in life is by doing it yourself or paying somebody to do it for you. And Lanfen has never been good with bureaucracy and rules and regulations (why do they have to make even being ill so complicated, with one doctor for this, and one for that, and another for something else - you need a secretary to make sense of it all!)

Although Lanfen is not a Buddhist her mother was and spent her last days breathing and meditating through her illness, which now seems to be a better option to Lanfen than what she saw her sister go through. But she can't bring herself to do it. She's tried and it's not really working; but then again, she's always known that she's not cut out for such things. So, she has decided to just try and carry on living as normal for as long as possible as she can't really see what else to do and there doesn't really seem to be any information out there anyway about this situation that she has found herself in.

Anyway she's not actually dying yet; she's just very ill. There's always a chance she'll feel a bit better tomorrow and talking about it will only bring it on. Although for some reason that she cannot quite understand – probably because the doctor made her promise, and she doesn't like breaking promises – she did visit the hospice. But only for one day; just to confirm that it was not for her.

It was on this first visit that she met and befriended Jim who seemed as cantankerous as her and who was, like Lanfen, a musician; and who is also not able to play his instrument very well anymore (Lanfen being an erhu* player and Jim, the Dobro**). When Lanfen returned home after that first visit, she realised that she had had, under the circumstances, a good day. And that she was looking forward to going again. Since then, their relationship has grown; both seeing themselves as something of the rebels of the group, often just sitting outside and looking in on the situation, not taking part in the activities on offer and not quite willing to admit that they are in the same situation as everyone else. Lanfen has found their conversations about life, love and music very helpful and she has come to look forward to them greatly.

But Jim is, as he has told her, 'further through the song than you', and has only returned to the hospice over the last week, after being absent for two weeks previous to this, to Lanfen's great consternation. Lanfen can see that he is really ill and is unable to talk as much as he used to. This has shaken Lanfen; seeing how frail Jim has become. Having spent many days with him recalling their individual adventures and believing that a good life is one where risks have been taken, she realises that this is what she wants; to still keep taking them. But that she does not know what this means in her situation and who, when Jim goes, will help her work this out.

Maybe one of the carers will have some suggestions. She just hopes that Jim will still be there today.

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* The erhu is two-stringed, bowed traditional Chinese instrument

** The Dobro is an American brand of resonator guitar, played with a slide rather than fingers on the frets.

Themes and concerns

Lanfen misunderstood the idea of hospice care and is learning of the benefits and activities on offer.

She has a lack of trust in health system and also finds it difficult to engage with health care bureaucracy.

She values her privacy but has embraced care on her terms.

Lanfen has little desire to consider the potential course of illness and death.

She'd rather retain some risk in life than spend her last days medicalised or 'wrapped in cotton wool'.

She has thought, albeit fleetingly, about strategies for pain relief.

If/when Jim dies, she will lose a key friend and confidant as well as a trusted source of information and advice.

Points for Discussion

What do you think matters to Lanfen? And how might you explore this?

How would you explain about a hospice to Lanfen?

What could be done to help widen Lanfen's support network (e.g. relevant charities, groups etc.)?

What more might be helpful to know to help you support Lanfen? What questions might you ask?

How might Lanfen be supported to access all the help that is available to her as she becomes less well, whilst maintaining her unique sense of self?

Tawanda

Tawanda is a keen football player and football fan who is has cancer. He is no longer receiving treatment at the hospital, having been told they are unsure at this stage if there is any more treatment available. Although the pain has been getting worse Tawanda is confident that he will pull through and that God will give him the strength to carry on. Everyone has always known that Tawanda is a fighter. Ever since arriving here as a young boy with his aunt he has had to stand on his own two feet.

Furthermore, the fact that he has not received any news from the hospital suggests to him that he has a good chance of recovery, because they always treated him well and he is confident that if they think of a new treatment that might work they will let him know. His wife, Chibuzo, has told him that she overheard a nurse saying that there was nothing more they could do, and it was now just a matter of time. Chibuzo was rather shocked to hear this conversation. Tawanda has tried to console her; and thinks anyway that the nurse is not a proper doctor and doesn't know what the doctor knows.

Tawanda respects his doctor who has always encouraged his positive attitude. There was one time when he was going to talk about things with him, about what might happen to his wife if the treatment didn't work, but he could see that the doctor was being positive, and he didn't want to let him down. Everyone must all believe in the same thing and fight together. That's the way that you win. Through teamwork.

Today some friends from the football team he used to play for are coming round to watch a big match with him on the television and he is willing himself to be in as good a shape as possible. He is worried that he may let himself and them down a little. He feels that he has done this with some of the congregation at church who have been praying for his recovery which has not yet started to materialise. But even if he can't play football just now he can still offer advice from the side-lines once his body has started to recover or if a new cure is found. And the doctors are always finding these new treatments and will contact him when they have found something that they think will work.

He also knows that he needs to apologise to one of his friends, Darren, who will be coming; someone he played with at the heart of defence the year they won the league. During a visit last week Darren suggested to his wife, Chibuzo, that Tawanda was not dealing with the reality of the situation, that he could see that he was getting weaker and that perhaps they should talk to the doctor about what they could do to make the end of his life easier for them both when that moment arose. This confused and worried Chibuzo, like the time she overheard the nurse, because Chibuzo knows that such things shouldn't be talked about like this. That to start to think about such things is the start of a slippery slope. Tawanda was very angry; it was wrong to do this to his wife. If Darren wanted to say anything, he should have spoken to him and not her. And anyway the Doctor is the one who will decide when the right time is to talk about such things.

Tawanda is aware that Chibuzo is tired and can sometimes become very emotional with the work of looking after him. He jokingly calls her his 'trainer' because she has become an expert on the peaks and troughs of his energy levels and mental well-being. Yet this moment of confusion for Chibuzo, because of Darren's thoughtlessness, also threw Tawanda, and in a moment of weakness he wrote down everything that he wanted to happen if he did die. Not just the funeral and what happens afterwards but the actual days leading up to his dying.

He hasn't given this to Chibuzo, and he hasn't told her about it. But he has kept it. Now that he's written it, it would be stupid to throw it away. He has also decided that Chibuzo should let his organs be donated. That maybe he can help a young person who is unwell. That maybe this will help them run around a football field or engage in some other kind of sport as he would like to. He is not sure about the religious teachings considering this, but it is something that he has decided on. And he is pleased that he has done that.

He rang Darren and told him never to say things like that to his wife again. That although he was a good footballer, he never had the same level of commitment as Tawanda; and never understood his faith. That the rest of the team that have come to his house have known better. Even though some are non-believers, and the others are of a different faith to him, they know the importance of a positive mindset. That you never win anything if you go into a game fearing defeat.

But it is not just all about his inner strength; he knows that. It is ultimately in God's hands. It is He who gives life and He who determines it will be taken away. Tawanda's job is to stay positive and to keep praying. And he has forgiven Darren, as he knows he should. It is a time to embrace ones love of friends. He just hopes the match today won't go to extra time.

Themes and concerns

Tawanda has a strong belief in God and in the power of positive thinking, and that contemplation of 'end-of-life' matters is greatly at odds with this outlook.

His doctor goes along with Tawanda's stance of hope, further perpetuating the absence of EOLC consideration.

Another HCP is overheard expressing a more pessimistic scenario which is upsetting for Chibuzo. She is struggling and Tawanda is keen to protect her.

Tawanda finds himself in a 'stage' of care between end of cancer care and end-of-life care – with the potential to feel somewhat adrift in the system.

Despite a predominant stance of hopefulness Tawanda does give a little forethought as to his future, although seeing this a weakness and failing his church and congregation.

Points for Discussion

What do you think matters to Tawanda? And how might you explore this?

What could be done to support Chibuzo?

What might have happened if Tawanda's wife had not told him about her overheard conversation- what impact could this have had?

What more would it be helpful for you to know to help support them both? What questions might you ask?

Appendix 1: Evaluation and Feedback

We would really value your feedback so that we can learn from your experience of using these resources and refine them further.

Please send you feedback to research@loros.co.uk

1. Can you please provide a brief description of the context of your use of the learning guide?

   (e.g. Self-directed learning, facilitating a group, teaching communication skills)

2. What parts of the learning resources did you use?

3. What did you find most useful about the resources?

4. Were there any additional 'points for discussion' that you would suggest we add that arose in your learning event?

5. Are there any other suggestions for improvement of the resources?

6. Will you recommend the resources to colleagues?

7. Please give a score for the resources overall (0-10)

Many thanks for your feedback. It is much appreciated and invaluable.