



# Supporting people with limited English in their end of life care

A learning guide for health and care professionals

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# Introduction

This learning guide, the <u>accompanying powerpoint slide sets</u>, <u>videos</u> and an e-learning module provide a blended learning package for health and care professionals about supporting people with limited English who are in the last year of their life. This work stems from 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 *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. You can read more about the findings of the study on page 7 and <u>access other learning resources</u> to support development of culturally competent practice.

An important recommendation of the *Thinking Ahead* research was to enhance health and care professionals' skills and confidence in working with interpreters. This is likely to improve culturally appropriate care and improve equity in end of life care for patients who have limited English.

Effective communication in emotional consultations is particularly challenging when language differences exist, necessitating the use of interpreters (Matthews, Baken, and Ross, 2020). Clinicians may feel insecure and use translation applications, but these may be insufficient in specialized palliative care language (Islam, Taylor, and Faull, 2021). Relying on bilingual family members poses confidentiality and emotional burden issues (Chaturvedi, Loiselle, and Chandra, 2009; Rimmer, 2020). Good practice means working with professional interpretation services to support empathetic communication, especially in breaking bad news and advance care planning contexts (Latif et al., 2022).

Whilst communication skills are vital in palliative care with all patients and families, training for professionals in these skills often fails to prepare them for transcultural interactions and interpreter-mediated communication. This can leave clinicians uncertain and ill-equipped in end-of-life discussions and decision-making (Islam, Taylor, and Faull, 2021; Kai et al., 2007).

# 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, especially doctors and medical students. However, some of the resources will be useful for any staff who work with interpreters with patients and families.

#### 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.
- Resource 1: Good practice in working with interpreters: Recorded powerpoint presentation in longer and abridged formats. A slide set of the above presentations is also available
- Resource 2: Nuances in working with interpreters: <u>Video</u> of a conversation between Professor
   Faull and Bini Gutaure, the Manager of interpreting services at Leicester Partnership NHS Trust
- Resource 3: Personal reflection of being a relative: <u>Video</u> by an IMT doctor
- Resource 4: A Family Story: Balwinder. This case scenario, based on the experiences of participants in our Thinking Ahead project is described on page 13 of this learning guide. A powerful first person audio recording is available in a long or abridged versions <a href="here">here</a>, together with transcripts. The long story is around five minutes and the abridged version around two minutes. The story is useful to promote reflection and discussion about family and professional interpreting.
- Resource 5: Scenarios for use in simulation learning of working with an interpreter for doctors
  and specialist palliative care practitioners are described on page 16. The three scenarios are
  areas of palliative care practice that are commonly encountered by clinicians: Symptom
  management, talking with a concerned relative and breaking the news that someone is so ill
  that they may die.

e-learning Communicating with non-English speaking patients <a href="https://portal.e-lfh.org.uk/Component/Details/818411">https://portal.e-lfh.org.uk/Component/Details/818411</a>

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)

#### 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*<a href="https://learn.nes.nhs.scot/50422/person-centred-care-zone/spiritual-care-and-healthcare-chaplaincy/resources/multi-faith-resource-for-healthcare-staff">https://learn.nes.nhs.scot/50422/person-centred-care-zone/spiritual-care-and-healthcare-chaplaincy/resources/multi-faith-resource-for-healthcare-staff</a>

#### **Feedback**

We would love to hear about how you have used the guide for learning and resources, what the impact has been and any ways that you would suggest to improve them. Please do send us your evaluation and comments via this <u>Microsoft form</u>

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

People from the diverse ethic communities in our study told us that they desire personalised, compassionate and holistic end-of-life care. The well established holistic (physical, spiritual, psychological, social) framework that guides us in how to support people with palliative care needs holds true in diverse cultural and faith contexts. 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. 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

People with advanced, terminal illness in our study predominantly told us they wanted 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, 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 families 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; also common was concern about being looked after by strangers who didn't care or understand their values and needs.

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.

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?

# Personalising care and communication

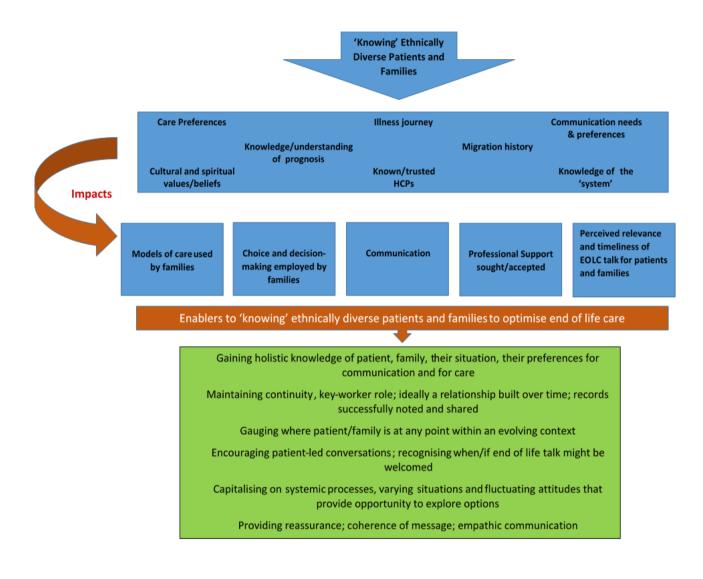
Each person will have their own set of unique characteristics, hopes, fears, and knowledge when they engage in the healthcare system. Each will be at a particular place in their illness journey and may have distinct preferences for care and possibly a need for differing ways in which these matters might 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; they 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 influence access to trusted relationships with individual professionals. People 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 how they communicate and 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.

This learning guide and resources aim to support development of personalised, culturally sensitive communication where a language barrier between the person and the professional will increase the complexity of effective communication and personalisation of care.

A key message that came from our research participants was the importance of compassion and empathy. Feeling 'known' and being 'seen' with due regard and respect mattered greatly 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. Effective communication is pivotal in this. These points are summarised Figure 1 below.

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



# The importance of interpreters

Interpreters play a crucial role in facilitating effective communication between healthcare providers, patients, and their families when language barriers exist. The importance of interpreters in ensuring personalised and equitable end-of-life care can be summarized in several key points:

#### • Improved Communication:

Interpreters help bridge language gaps, ensuring that healthcare professionals can communicate important information to patients and their families about their illness, prognosis and care and treatment decisions accurately and comprehensively.

They enable patients to express their needs, concerns, and preferences, fostering a more thorough understanding of the individual's wishes and goals in palliative care.

#### • Culturally aligned care:

Interpreters contribute to cultural competence by understanding and respecting the diverse backgrounds and beliefs of patients and their families.

They help healthcare providers navigate cultural nuances, ensuring that care plans are tailored to meet the unique preferences and values of each individual.

#### • Promoting Autonomy:

Interpreters play a critical role in ensuring patients fully understand their medical condition, treatment options, and potential outcomes.

This helps in promoting patient autonomy and involving them, and/or their family according to their wishes, in decision-making processes related to their end-of-life care.

#### Facilitating Family Discussions:

Palliative care often involves family discussions about end-of-life care, which can be emotionally charged and complex. Interpreters assist in conveying sensitive and complex information in a way that is fully understood by all and facilitating inclusive discussions between professionals and family members.

#### Reducing Misunderstandings:

The presence of interpreters helps minimize the risk of misunderstandings that may arise due to language barriers and conceptual translatability (such as what palliative care is, what a hospice is, intentions in use of morphine), ensuring that accurate information is conveyed and understood and reducing the likelihood of medical errors and cultural insensitivity.

#### • Ensuring Access to Support Services:

Interpreters assist in connecting patients and their families with support services, such as counselling, spiritual care, and social services, ensuring that they receive comprehensive and holistic palliative care.

# A family story: Balwinder

First person audio recordings and transcriptions can be found here.

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 do or, 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.

Direct communication with the patient 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.

#### Points for Discussion

Why has a professional interpreter not been used in this situation?

What are the pros and cons of professional and family interpreting in your experience?

How might you explore what Balwinder is feeling and what might you offer?

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

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

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

# Scenarios for simulation learning

#### Please note

- The scripts are an outline and provide a basis for the simulation that will need to be developed further on the training day.
- In most part the interpreter script has not been added as a distinct part of the conversation as it repeats the professional's words in the 2<sup>nd</sup> language. Text is added where words are differently translated.
- The scenarios are faith but not gender specific
- The scenarios are suitable for doctors at all levels and nurses specialists
- The actor and the interpreter will share the same language. The same Asian, African and Eastern European language can be used for scenarios of different faiths
- This symbol [] indicates where substitutions can be made

#### Scenario 1. Assessing symptom management for dying patient in hospital ward

#### Overview

**Patient context**: [Mrs] [Name to be agreed] is an [Indian Punjabi] Muslim who has limited English. She has advanced lung cancer and has been admitted with shortness of breath. She is on a syringe driver. The doctor has been asked to see if her symptoms are well managed.

**People:** [Mrs] [Name], her [daughter] who does speak English, Interpreter and [doctor].

#### Illustration of poor practice in working with interpreter

The remit here is that although the doctor is empathic and communicates well in English they do not work effectively with the interpreter to achieve the best for the patient and 'cues' about the patient are missed.

The scenario may be used for people to discuss what things were not optimal/effective and what could be improved.

A check list of elements should be provided as a summary.

Checklist of elements that should be identified and discussed:

- The doctor/nurse does not give the interpreter an opportunity for a briefing
- The interpreter sits beside the patient.
- The daughter/son is side-lined
- The doctor/nurse speaks to the interpreter not to the patient

- The interpreter is a 'passive' role and does not work with the doctor to help explore things that the patient raises.
- There is no focus on spiritual/cultural context so lack of personalisation of care.

Script outline

{Outside patient room}

Doc to interpreter: Ah good you're here. Thanks for coming. Let's go in.

{Enter room}

{Interpreter follows and sits beside patient at suggestion of doctor/nurse who stands at end of bed.}

Doc: Hello. I'm Doctor Williams. I'd like to understand how you are today. I have an interpreter with me so hopefully we can understand it each other well. I hope that's OK? I'm sorry I don't speak [Punjabi].

{Patient looks to daughter} and both say: Thank you doctor.

Doc: Ok. {looking to interpreter} Can you ask her if the pain is better please?

Interpreter: Is your pain better?

Patient: In English: It's OK. Talks to daughter in Punjabi: I need to bear this. God is great.

{Interpreter does not interpret the Punjabi part}.

Doc: That's good. Is there anything you want to ask me?

Interpreter: Do you have any questions?

Daughter: In English: When can she go home doctor?

Doctor: To daughter: I think tomorrow if that's ok?

Daughter: In English: Yes that will be good. To Mother in Punjabi: You are well enough to go home

tomorrow.

Patient: To Daughter: God be praised.

Doctor: To interpreter. *Is there anything else she wants to discuss?* 

Interpreter: Do you want to ask anything else?

Patient to doctor: In English: Thank you doctor. In Punjabi: It is God's will and I pray for his mercy.

Interpreter: She is accepting and praying to Allah

Doctor: I am glad that you are comfortable and wish you all the best. Goodbye

Interpreter: translates above.

Patient and daughter: in English: Goodbye doctor and thank you.

{Exit room}

Doctor: To interpreter. Thanks for your help. Have a good day.

#### Illustration of good practice in working with an interpreter

The remit here is that although the doctor works effectively with the interpreter to achieve the best for the patient, the style of communication permits 'cues' about the patient to be explored.

The scenario may be used for people to discuss what things were optimal/effective and what helped achieve the good outcomes for the patient, relative and interpreter.

The principles of good practice in working with an interpreter that have been demonstrated could be identified by discussion.

{Outside patient room}

Doc: Ah good you're here. Thanks for coming. Before we go in could we have a brief discussion. Just to check first that you speak the same language as the patient?

Interpreter: Yes we both speak Punjabi

So just to warn you that this is a very sick woman. I expect that she will die in the next few weeks. I need to be sure she is comfortable and that we are providing the care she needs.

Interpreter: Thanks. I haven't been in this situation before. This will be hard for them I would think.

Doc: Yes, it will likely be a difficult conversation, so it would be helpful to me if you can help pick up on questions or worries that they have and help me understand them if I'm missing something because I don't share the faith or culture. Can you do that?

Interpreter: Yes I can work in that way if you direct me although I myself am Sikh and she is Muslim.

Doc: please translate everything that is said in Punjabi so I am aware of everything that is said

Interpreter: Yes of course. I will tell them that.

Doc: Ok is there anything else you need to know or guide me on before we go in?

Interpreter: I notice her daughter is here. She speaks English. How shall we work with her?

Doc: Let's see how she wants to be involved but I need to be sure that I am hearing what Mrs {name} says and this will probably be really emotional for her so we need to support her and not expect her to interpret.

{Enter room}

{Interpreter follows and stands beside doctor.}

{Note Interpreter says everything that is spoken in Punjabi by patient/daughter}

Doc: Hello. I'm Doctor Williams. I have an interpreter with me today so we can all understand each other well. I hope that's OK? I'm sorry I don't speak Punjabi.

Interpreter: Hello I am [name] I will interpret everything the doctors says for you and I will interpret things that you say in Punjabi for the doctor to understand.

She says: I'm Doctor Williams. I have an interpreter with me today so we can all understand each other well. I hope that's OK? I'm sorry I don't speak Punjabi.

Patient looks to daughter and both say in English: Thank you doctor.

Doctor: I know that your daughter speaks English and Punjabi well so I'm pleased that she can also help us with making sure you understand things and ask things that you want to.

Interpreter translates doctor speak

Patient to daughter: in Punjabi: Is that OK?

Interpreter translates doctor speak

Daughter: In English: Yes

Doc: Ok. Thank you. How is your pain today. is it better?

Interpreter translates

Patient: In English: It's OK. Talks to daughter in Punjabi: I need to bear this. God is great.

Interpreter translates patient Punjabi speak

Doc: It's good that you feel it's OK. What is it that you are bearing though? Can I help you more?

Interpreter translates

Daughter: In English. My Mother is sure God will help her.

Doctor: Thank you. I think maybe we should speak in Punjabi to be sure your mother is part of this discussion. Your daughter is telling me that you look to God to help you. Can you help me understand that a bit more please?

*Interpreter translates* 

Patient: All is in God's hands.

*Interpreter translates* 

Doc: I can hear that your faith is very important to you. My understanding of Islam is of the importance of preparation. Might we talk more about how to help you with that?

*Interpreter translates* 

Patient: I listen to the Qur'an. That is all I need doctor.

Interpreter translates

Doctor: You don't need to be suffering. I can increase your pain medicine. Is that something that would help? It is my understanding that this medicine is allowed in Islam. It's OK to use it.

Interpreter translates

Patient in English: I am OK.

Doctor: If you want to speak with an Imam for guidance on this I can arrange that.

Interpreter translates

Patient in Punjabi: I would like that. Thank you.

Interpreter translates

Daughter: In English: When can he go home doctor?

Doctor: Your daughter is asking when you can go home. If that's something you want too? I think tomorrow if that's ok? I will ask your palliative care nurse to see you at home to make sure your pain is ok.

Interpreter translates

Patient: Yes that will be good. God be praised.

*Interpreter translates* 

Doctor: To interpreter. Is there anything else he wants to discuss?

Interpreter asks: Do you want to ask anything else?

Patient to doctor: (English) Thank you doctor. (Punjabi) It is God's will and I pray for his mercy.

Interpreter: He is accepting and praying to Allah

Doctor: I wish you all the best. Please do know we can help with your pain. Goodbye

Interpreter translates

Patient and daughter in English: Goodbye doctor and thank you.

{Exit room}

Doctor: To interpreter. Thanks for your help. Was there anything that you think I missed? I do think she's in a lot of pain. I wonder if I should do more with the medications.

Interpreter: I can't comment on the medications doctor. What she said about his faith being of utmost importance is quite typical in my experience as people prepare for meeting the angels and the next life.

Can I just check that you are OK. It was a sad conversation?

Interpreter: Yes thank you. A little sad for them of course but I felt privileged to help them. It reminded me of my grandmother but I am OK thank you.

#### Scenario 2. Speaking with a concerned relative

#### Overview

**Patient context**: [Mrs] [Name] the [wife] of a [Sikh] patient who is in the last days of life and not conscious. [She] has asked to speak with you about the syringe driver

**People:** [Mrs] [name], Interpreter and doctor/nurse.

{Outside patient room}

Doc to interpreter: Ah good you're here. Thanks for coming. Before we go in could we have a brief discussion. Just to check first that you speak the same language as Mrs [name]?

Interpreter: Yes we both speak Punjabi and I'm a Sikh too.

So just to warn you that Mrs [Name's] [husband] is very sick. I expect that [he] will die in the next few days. I am not sure why [she's] asked to see me.

Interpreter: Thanks. I haven't been in this situation before.

Doc. Is there anything about the Sikh faith and morphine do you know?

Interpreter. I'm not an expert of course but I don't think so. Some people do fear morphine though.

Doc: Ok thanks for that.

{Enter room}

[Interpreter follows and sits beside doctor so both facing Mrs [name]].

Doc: Hello. I'm Justine Williams the doctor. I have an interpreter with me today so hopefully we can understand it each other well. I hope that's OK? I'm sorry I don't speak Punjabi.

Interpreter translates

Mrs [name]: Thank you doctor. I just want to understand what your' doing to him that's making him so sleepy. Hhe does not seem to be getting better. That machine is making him ill.

*Interpreter translates* 

Doctor: He is very ill I agree. I am sorry that we are not able to make him better.

*Interpreter translates* 

Mrs: But you are using morphine, a poison to make him ill.

Interpreter translates

Doctor: You are right that we are using morphine. It's to help with the pain he has in his bones from the cancer. We are using it in a small dose. Can you tell me more about why you think it is making him ill?

Interpreter translates

Mrs: My father died after they started morphine. It kills people.

Interpreter translates

Doctor: I can see you are very distressed by this.

Interpreter translates

Ms: Yes he is so ill. I fear I am loosing him.

Interpreter translates

Doctor: I am sorry. He is very near to dying from the cancer

 $Interpreter\, translates$ 

Mrs: It is the morphine that is killing him.

Interpreter translates

Doctor: I am so sorry he is so ill, but it is the cancer that is causing this not the morphine. We could change the morphine a little bit to see if that makes a difference but if the pain increases again can we agree that we change it back?

Interpreter translates

Mrs: Is there no other drug you could use?

Interpreter translates

Doc: I can do that yes. It's similar in the way it works on pain to morphine. Called Oxycodone. Some people are less sleepy on it. we can change to that.?

Interpreter translates

Mrs: I think so yes

Doc: I don't want to mislead you at all though. He is very, very poorly from the cancer. I think it's important you and your family spend time with him and make preparations. Is there more we can do to support you in that at all?

Interpreter translates

Mrs: I will talk to my children and his brother. Thank you doctor.

{Shake hands }

{Exit room}

Doctor: To interpreter. Thanks for your help. Was there anything that you think I missed?

Can I just check that you are OK. It was a sad conversation?

Interpreter: Thank you doctor. I think I will go for a cup of tea before my next client but I am OK. It is just very sad.

#### Scenario 3: She is so ill that she may die: Breaking bad news by phone

**Patient and context**: [Mrs] [Name] is a Pakistani Punjabi Muslim who has limited English. [Her] [mother] was admitted today with pneumonia and heart failure. [She] has had diabetes, heart failure and kidney problems for a long time and is unlikely to respond to treatment.

The Doctor needs to update Mrs [name] on the phone.

People: Mrs [name], Interpreter and doctor.

{Start at time point when doctor is waiting for interpreter to join:}

Interpreter: Good evening.....

Doctor: Hello I'm wanting to speak with a Mrs [name], who speaks Punjabi, about her mother who has been admitted today and is seriously ill. I need to explain to her that she might die.

Is there anything that you and I need to discuss before we ring him?

Interpreter: I think that's sufficient detail thank you.

Doctor: Can you tell me how you will open the conversation please?

Interpreter: Hello I am xxxx a professional interpreter. Is that Mrs [name]. I have the doctor from the hospital today who wants to talk with you about your mother. Can we go ahead?

Doctor. oK I will ring Mrs [name] now. Please introduce yourself and me when she answers

{Ring}

Interpreter: Hello I am xxxx a professional interpreter. Is that Mrs [name]. I have the doctor form the hospital today who wants to talk with you about your wife. Can we go ahead?

Mrs [name]: Yes please

Interpreter translates

Doctor Hello I am Dr Sian Nevis. Can I check that I am speaking with Mrs [name]? Can you confirm your address please and your mother's name.

Interpreter translates

MrS. Yes I am she. My address is ... my mother is called []

Interpreter translates

Doctor: Thank you. Is there anyone in the house with you?

Interpreter translates

MS. No I am alone. My son is away.

Doctor: Ok. I need to talk with you about your mother's condition. Are you able to do this now? or would you like to get a friend or neighbour to be with you? Maybe you would also like to come in and speak with me?

Interpreter translates

MS: doctor I am too unwell myself to come and visit. Please go ahead doctor. I know she is very ill.

Interpreter translates

Doctor: I'm so sorry to have to tell you that She is very ill. Her breathing is very bad and she is very sleepy.

Interpreter translates

MS: I am sad for her. What can you do doctor?

Interpreter translates

Doc: It seems her body is too sick and that the medicines, antibiotics, are not working.

Interpreter translates

MS: I know you will be doing your best doctor.

Interpreter translates

Doctor: I am very sorry but I don't think she is likely to get better. I think she is so ill that she may die soon. I wish it were better news.

Interpreter translates

MS: Silence

Doctor. Are you OK Mrs [name]. I know this will be upsetting. Would you like me to go on?

Interpreter translates

MS: doctor I am sorry that I am too unwell myself to come and visit.

Interpreter translates

Doc: Can we do anything else for you? Sometimes we use a video phone so you can speak or see. Can you use your phone or ipad for this? What would you like?

Interpreter translates

MS. I will contact my son and he will decide doctor. You are very kind.

Interpreter translates

Doc: Can we please have his phone number so we can call him if things change with your mother? Or Would you like us to call you? This must be so hard for you when you can't call us because we don't share the language.

Interpreter translates

MS: It has been a good life. I am OK. Thank you doctor his number is .....goodbye.

Interpreter translates

Doc. Bye.

Doctor to interpreter: Thank you for that. It felt very sad

Interpreter: Yes doctor. I'm glad I could help. Goodbye.