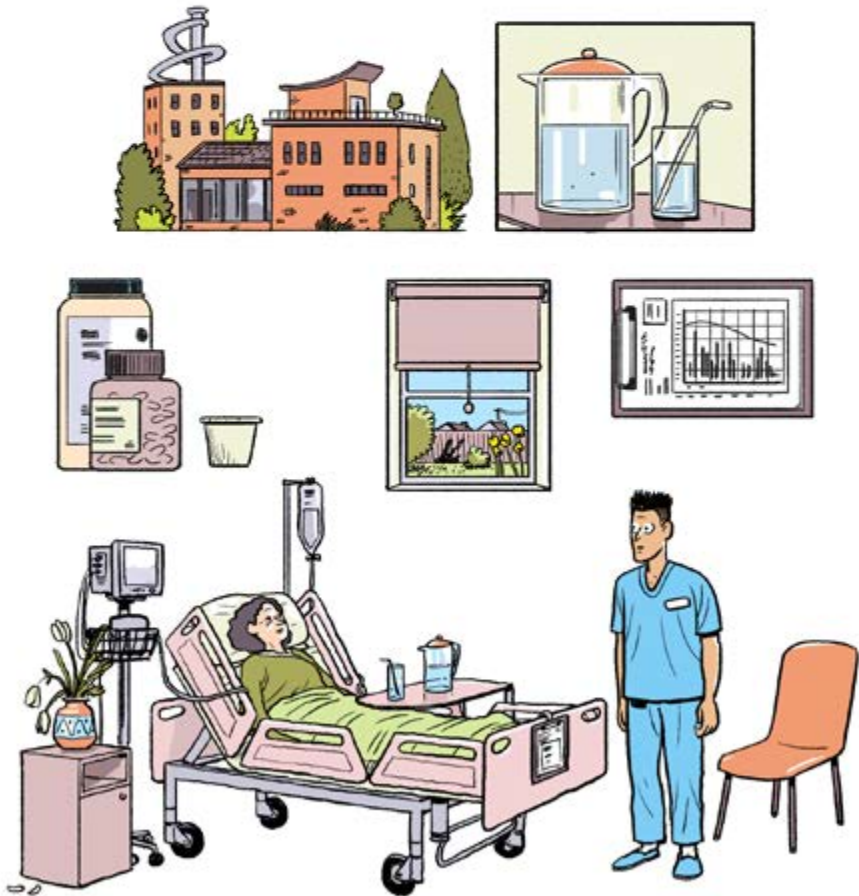




End-of-Life Conversations



Making conversations easier



“

I was particularly grateful to the Oncologist who took the time to take us to a quiet area to explain what was happening. He was very clear that dad was actively dying and advised us to bring his loved ones around him so they had a choice to spend time with him. A blessing for us all. We thought we had a few months, or weeks, turned out to be days. For that I will be eternally grateful.

(A letter from a patient)

“

Summer Haiku

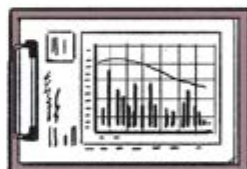
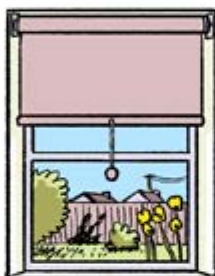
Silence and a deeper
silence when the
crickets hesitate

Leonard Cohen (1968)

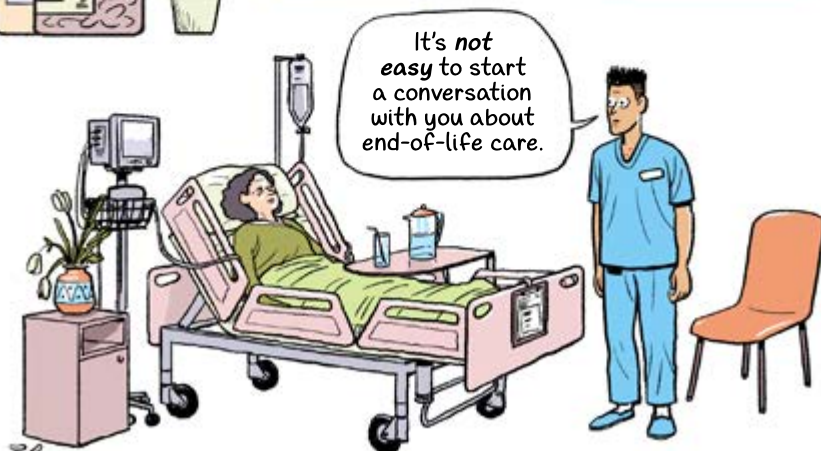
Leonard Cohen's Summer Haiku, which can be found in his collection, *The Spice-Box of Earth*, is a brief, evocative poem that captures a fleeting moment, a pause in time. The crickets are the key element of the natural world's soundscape, and their "hesitation" creates a moment of heightened awareness and silence. The poem's brevity and simplicity invite us to think about the transient nature of life and the power of the pause and use of silence.



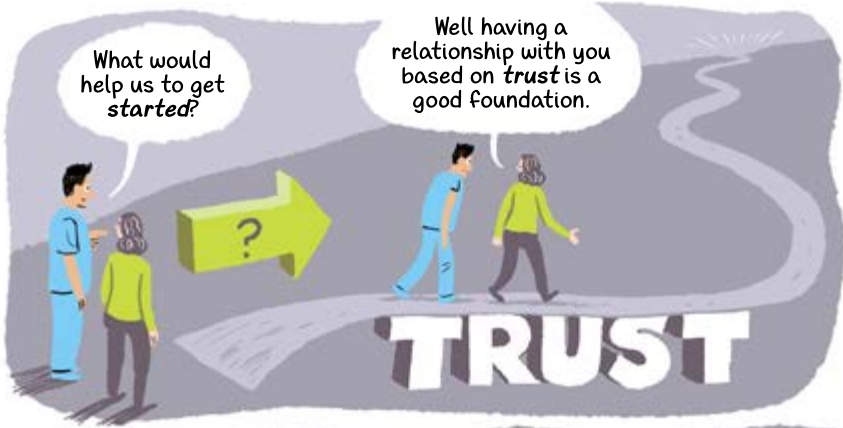
End of life Conversations

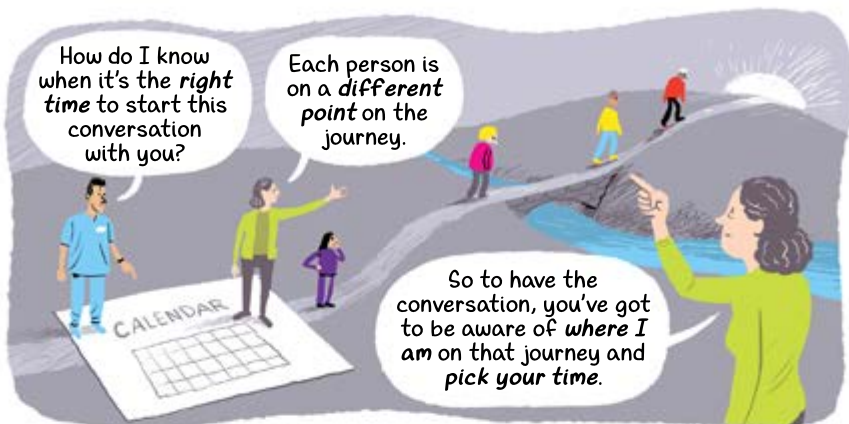


Introduction











Preparing for the conversation

Managing time

It's *not* easy for me to say this.

Go on...



Having these conversations can take a lot of time.

Sometimes I will even *avoid the conversation* because I don't know what's going to *happen* or *how long* it will take...



It can save you time if we start that conversation *early on*, so my family and I feel *prepared*.



You'll need time...



...to speak *slowly and clearly* and answer my *questions*.



Ok, so where possible, it's helpful to *plan* an end-of-life conversation and *how much time* is needed for it.

That makes sense.





Preparing yourself

How can I prepare myself?

Like you would for any conversation!



So I familiarise myself with your **background and healthcare history**...

...and prepare a **quiet, private space?**



INFORMATION



ENVIRONMENT

Yes and prepare yourself to **connect** with me.

You mean **put away** my phone and pager?



...take a **breath** to disconnect from what might have happened before...

...you could have just had a **tricky conversation** with another patient or an **argument** with a colleague...

Yes that and...



So...**put away** my phone and pager...

...take a **breath** to ensure I am in the right frame of mind.



Yes...

...then take a **second breath** to pause...

...to become **still and silent**.



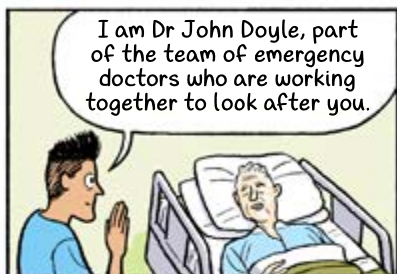




Starting the conversation



Start with a *warm greeting*, introduce yourself by *name and role*.



Check *my name* and how I like to be called.



Ask who is *with me* and use my name to build connection.



Ask permission to sit down, make and maintain eye contact with me and my family.



Acknowledge that this is a difficult time for us.





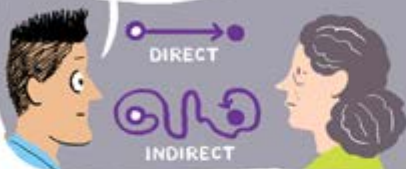
Setting the agenda (judging readiness for the conversation)

Is it better for me to be *direct* or approach the conversation in an *indirect* way?

Some people look *terrified* at the mention of end of life...

I prefer a *direct* approach. I want you to be *honest and open* but not *blunt*...

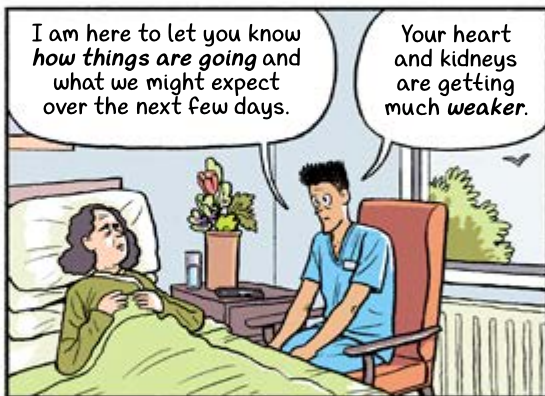
...so balancing reality with hope.



My patients know me as someone who is likely to call a spade a spade and expect *honesty* from me.

I am here to let you know *how things are going* and what we might expect over the next few days.

Your heart and kidneys are getting much *weaker*.

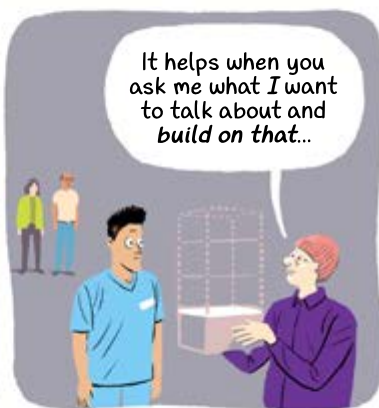


Ok but what if I try to bring up the subject and you shift away from it or don't respond to me?

Maybe briefly flag to me that you would like to have the conversation at another time.

This will give me time to think about it...





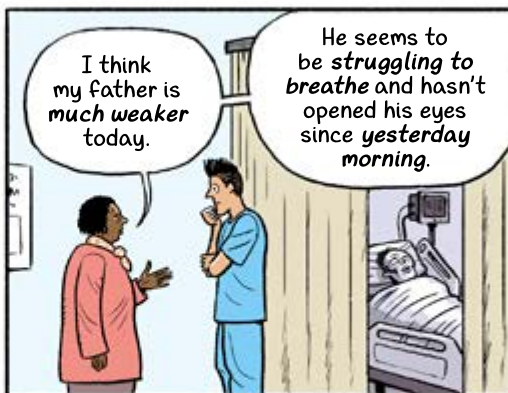


Sometimes you *say something*, and I can *respond* to that...



I think my father is *much weaker* today.

He seems to be *struggling to breathe* and hasn't opened his eyes since *yesterday morning*.



Then I *summarise your concerns*, explain my *goal* for the meeting and we can agree a *shared agenda*?



So you have noticed that your father is getting weaker and struggling to breathe.



That is also our main concern and I'd like us to talk about what the next steps are.



I prefer a *gentle, indirect* approach...



...so start with asking me about my *feelings* and my views about death...

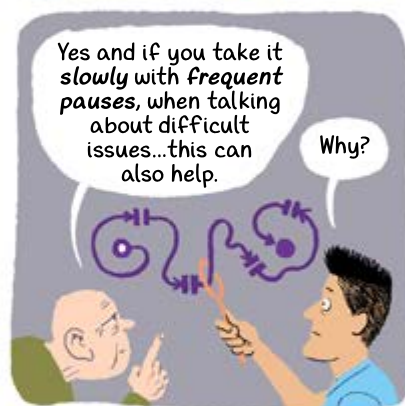


...listen for my *cues*...

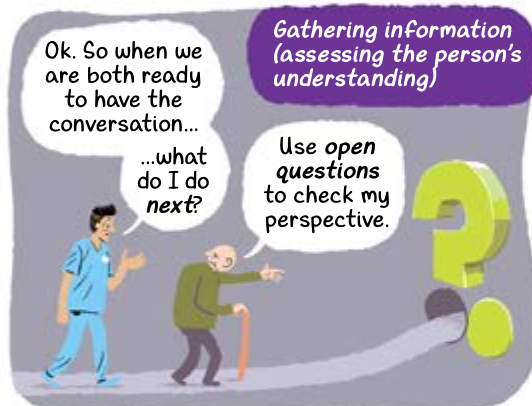


...*trigger moments* that tell you if I am *ready* for the conversation.



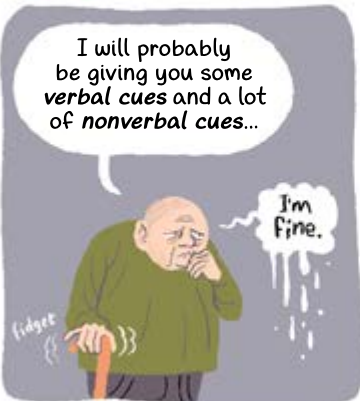








Ask me what I think about the *future*.





Demonstrating empathy

When you see and hear my cues, this is a third opportunity for you to *take a breath and pause*.



The pause allows you to attend to *what I am saying*, to notice my *emotional responses* and your own. To reaffirm your intention to *act with empathy*.



Why is this so important?

Pauses allow you to be truly *present* to me.



When you pause, you are less likely to *interrupt* me.

And pauses allow me time to *think* and get my thoughts in order!



Interruptions aren't good!

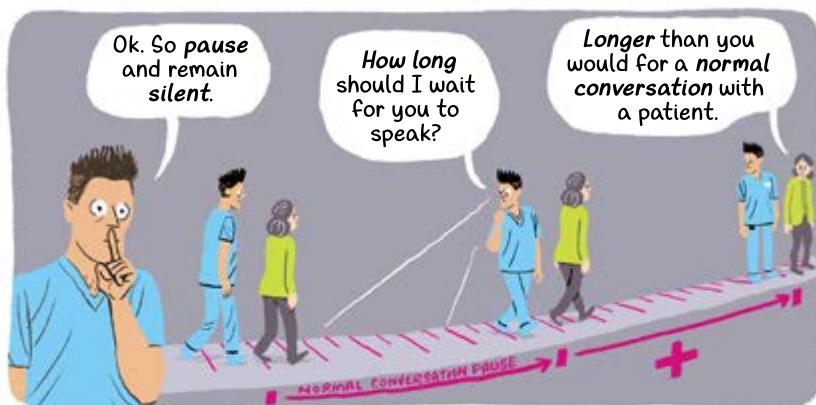
No!

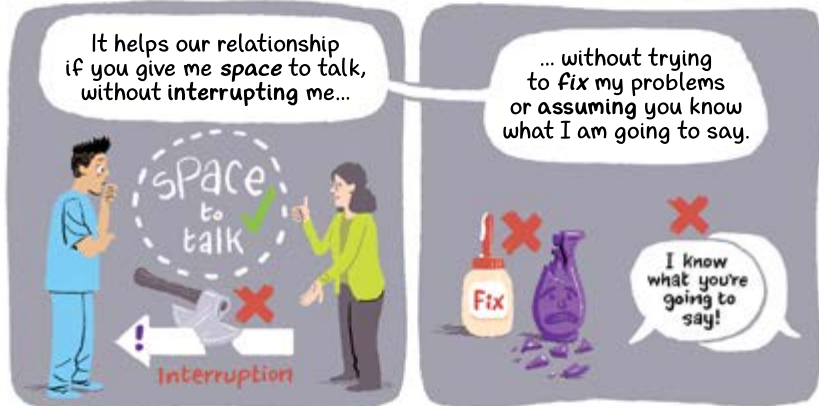
Fill the pause with nothing but *silence*.

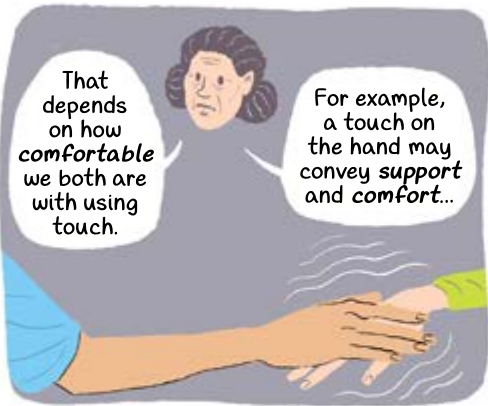
Silence is not just the *absence* of speech.

It is *respectful*, it shows *presence* and gives me the sign that you *value my input* and are prepared to *wait* for it.













Sharing information

Providing structure



You are very *familiar* with what happens in conversations like this. I am not.



How can I help?



Speak *slowly*.

Make sure I know what's happening *now* and what's going to happen *next*.

Now → Next

Organise what you are saying into *small chunks* of information.

I am here to let you know *how things are going* and what we might expect over the *next few days*.

If we need to talk *more*, then we can meet again *later*.

Aid recall and understanding

It's my job to explain things *clearly*.

If I use language that sounds *confusing*, please *stop me* so I can explain things better.



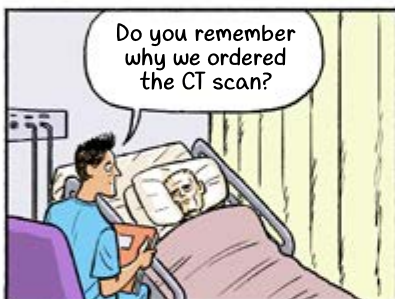
Ok so *organising* the information is important.

What is the best way to *get started* in sharing information with you?

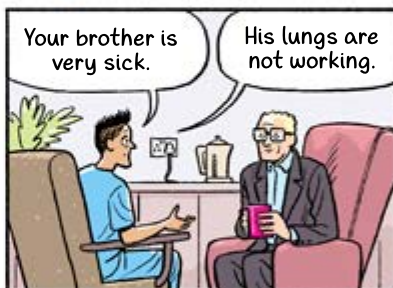
Start with asking permission.

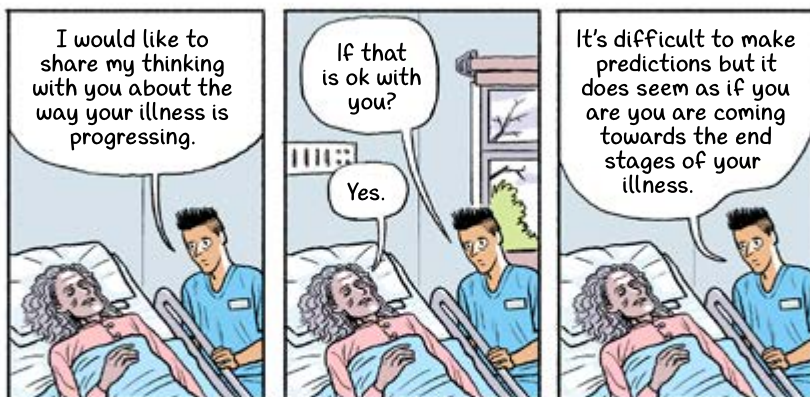


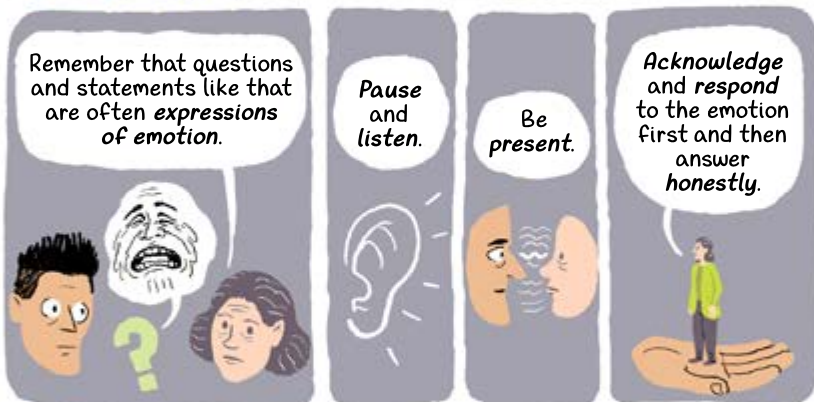
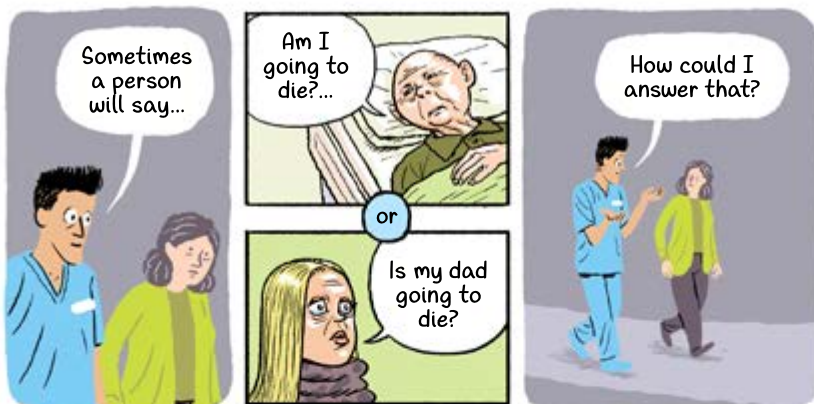
Then ask me what I know already and what my expectations are.



Give me small chunks of information with lots of pauses to allow the information to sink in.









Sometimes using a **wish statement** can be helpful in letting me know that you have noticed how I am feeling.





Begin with a *simple, general statement* of how I am.



Use *short phrases*—share one or two simple things first.



Do not use *medical jargon*.



Be *honest and direct* with me



Pause *frequently* — give me time to take in the information.



Use *diagrams* to make your explanations clearer to me.



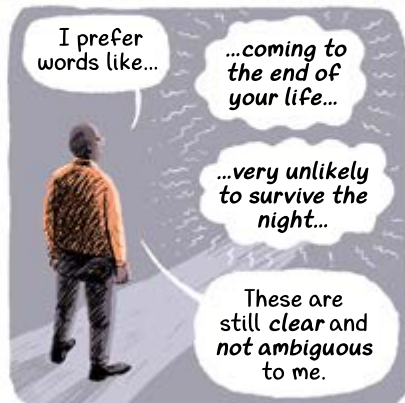
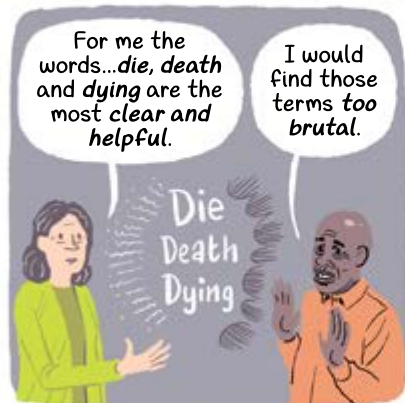


Tell me the **prognosis**, if you know this...

...or show that you share my **frustration** about **uncertainty**.



Explain what will **indicate worsening** of the condition.





How can I check if you are *taking in* everything I am saying?

First watch my *non-verbals*.

Do I look like I am *understanding and participating* in the conversation...



...or am I at a point where I might be *overwhelmed and needing time and support* before talking further?



Then *invite questions* from me and *acknowledge* that this is *difficult* for me to hear and talk about.

I have shared a lot of information with you.

Let me stop now and hear what questions you have.

How are you feeling about what we have discussed?

This must be really tough.



When the time feels right, suggest a move on to the next topic or stage of the conversation.

So in this situation, people often want to know what the next few days are going to look like.

Would that be helpful for us to talk about?



Incorporate the person's perspective



Ask what is important to me *right now*.







Hypothetical questions

Sometimes using a **hypothetical question** can help me to talk about the future



Tell me **some more** about that?



So you could describe a **hypothetical future situation** and then use that to ask about my **feelings or plans**.



By using words to emphasise the **imaginary nature** of what you are saying, it helps to create a **distance** between me and the fact that my illness is progressing and that I am going to die.



This distance makes it easier for me to talk about the topic.



Say you got so ill that you couldn't kind of make decisions for yourself...

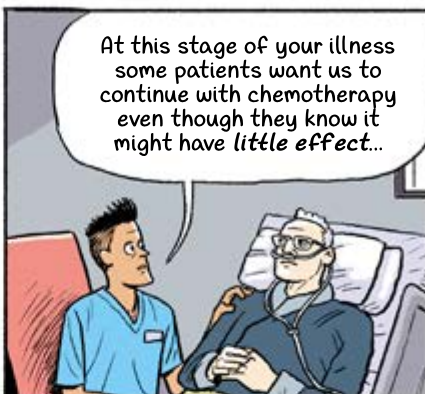


Who would you have to make them for you?



Who do you consider your **next of kin**?







Moving the conversation
towards comfort and support

...it's important to show that you are not giving up on me. That you will continue to give me the *best possible care* and that you are part of a *whole team* that are looking after me.



Talk like this can help *build and maintain* our relationship.



So...for people who have this condition, I like to see whether there is anything that we can do to make you more comfortable.



You sound *cautious*?

Well shifting towards comfort and support too *early* can *inhibit* talk about difficult things.



So maybe it's best to *delay* moving in this direction until we have discussed your *end-of-life concerns*?

Exactly!





Involving the family

What can I do to involve your *family* or check if that is what you want?



Well if it is a pre-planned conversation about end-of-life matters, you could *forecast the plan* to have the conversation so I can bring my family member with me.



Family discussions are good to make sure that everyone is on board.



Our preferences for family involvement will vary.

I want to have the conversation alone in order not to upset the family.



I want a family member to be present to ask the questions that I won't think of and to remember the details.



I would prefer you to deliver the news to my family members when I am not there.



I am the type of person who wouldn't want to have conversations about end of life - I would definitely want you to talk to my family.



I have dementia so I need you to be clear and open with my family.





Shared decision making and planning

What can I do to show you that we are working **together** to make these very important decisions?

Check in with me.

Explain **clearly** what is and is not possible.



I'm sorry to say, if he was at home, we wouldn't be able to give your brother the amount of oxygen he needs in order to be comfortable.



I wish it was possible to get your Dad home at this point.



We are not going to **disturb him** by checking his temperature and his blood sugars...



...and we are going to avoid disturbing all of you whilst you spend this **precious time** with him.

How does that sound?



If I or my family have talked about our **preferences**, for example regarding preferred place of death, then be **clear** about whether our preference is **feasible**, and what it would entail.



From what you have told me, you would like to be at **home** when you come to the end of your life.



To try to make that possible, we would need to...





Closing the conversation



Briefly *summarise* what we discussed.



Explain what will happen *next*, including when the next conversation(s) with staff will be.



Allow me or my family member to *correct* or *add* information.





Identify if there is **more** to talk about on another occasion.

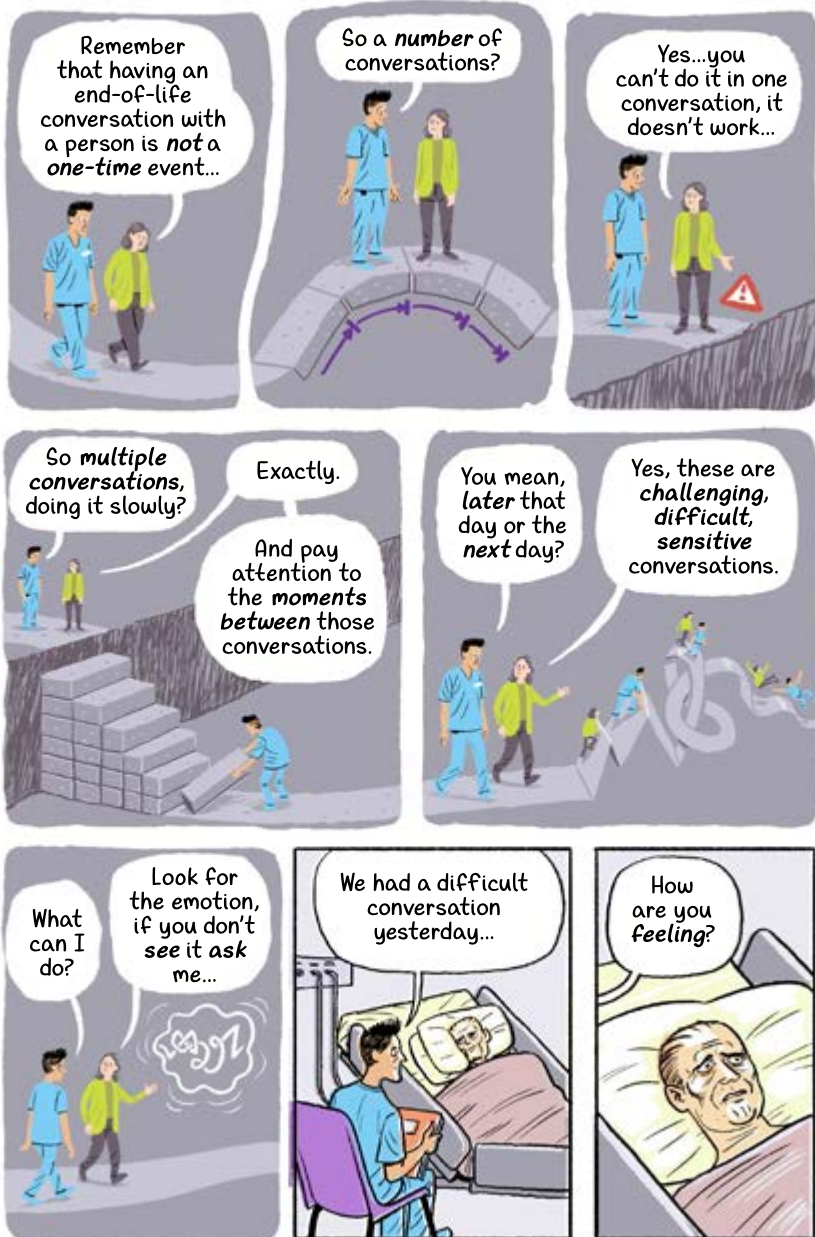


Encourage me to use available **resources**.

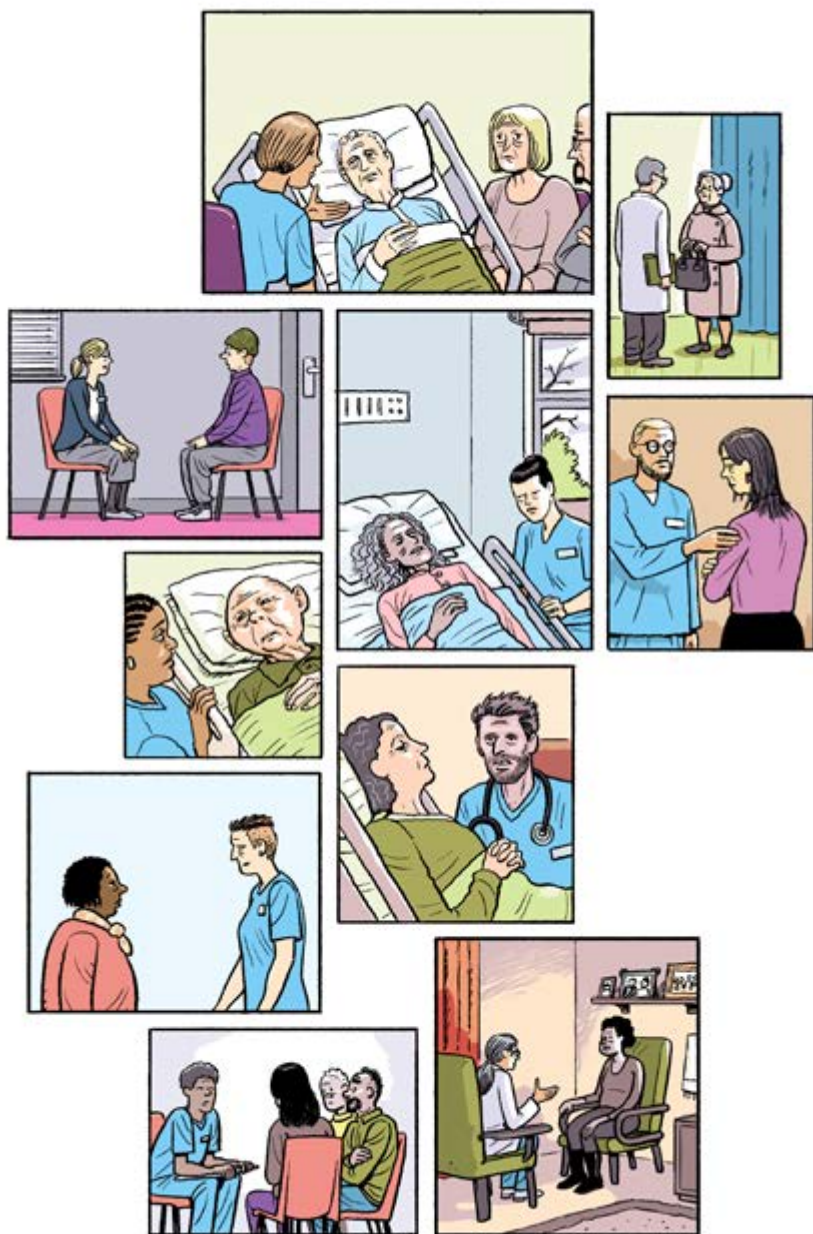


Emphasise **support**—that we are not alone.











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