National Healthcare Communication Programme

End-of-Life Conversations

GUIDING PARENTS TO PREPARE CHILDREN/YOUNG PEOPLE WHEN SOMEONE CLOSE IS DYING

A leaflet for healthcare staff

Making conversations easier

HSE

> *Children need adults to listen to their questions, to hear their stories, and to help them find ways to remember the person who died.*
>
> **Donna Schuurman**

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Preface

For brevity, we use the term “parent” here. The same advice applies if the child is primarily looked after by a caregiver who is not a parent.

This skills card covers **communication skills for conversations where professionals advise parents about communicating with children** when someone very close to them is dying.

The skills card contains a section detailing **advice that can be given to parents**.

Initiating the conversation

Preparation

Communication skills

- [ ] Prepare yourself
- [ ] Prepare the environment
- [ ] Prepare your information

Prepare yourself

- Be aware of your appearance; a professional, calm demeanour is important.
- Take a few moments to ensure you are in the right frame of mind for this conversation with the parent/caregiver.
- Remind yourself that, however skilled your communication, the parent/caregiver is likely to experience considerable distress and may show it in different ways. Their distress may also affect how they feel about talking with their child.

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Initiating the conversation

Prepare the environment

- Avoid interruptions – move to a quiet, private area where the parent/caregiver can sit comfortably.
- If possible, have age appropriate materials available (paper, pens, toys) that parents can later use with their child (for play, drawing, or memory making).

Prepare your information

- Clarify in your own mind the purpose of the conversation: building shared understanding with the parent/caregiver in a sensitive and supportive way, and **advising them on how to talk with their child**. Remind yourself you cannot fix the parent's/caregiver's feelings.
- Familiarise yourself with the clinical situation and family context:
  - Diagnosis, prognosis, and current plan of care for the dying person.
  - Who the key adults are for this child, including who has parental responsibility, and who is likely to have the conversation with the child.

Initiating the conversation

Prepare your information *(Contd.)*

- Check what the child has already been told, what the support needs are for the child, and what the parents/caregivers hope will be covered today, and by whom.
- Consider: Who is best placed to share the information? Who plans to be present? Is the unwell person able to take part in the conversation?
- Read information from colleagues, relevant notes, or letters.

TIP

Set aside adequate, protected time for a face to face meeting with the parent/caregiver. Parents often need time to process information, ask questions, and think through how they will talk with their child/children.

Initiating the conversation

Establish initial rapport

Communication skills

- [ ] Warm greeting
- [ ] Introduce yourself
- [ ] Check names and how they like to be addressed
- [ ] Use names when demonstrating empathy
- [ ] Clarify who is important to the child (name/relationship)
- [ ] Tell the parent/caregiver what you have done to prepare for the conversation

- Explain who you are, your role and the team. Even if you have met before, re-introduce yourself in clear, simple language.
- Ask/check names and relationships to the ill person and to the child.
- Acknowledge that this is a difficult time for everyone.

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Initiating the conversation

Hello, I'm _____, I'm a [nurse/doctor/social worker] in the team looking after [dying person's name]. One of the things I do is to advise parents on how to talk with their children about what is going on when someone very close to them is very unwell.

You might add:

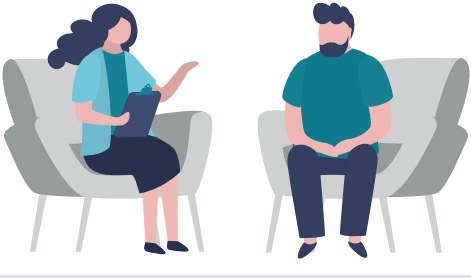
I've read through the notes and seen your [relative] this morning. Would it be alright to talk through ways to talk with [child/children's name] about this?

Initiating the conversation

Explain why it is important to talk with children

- Explain why it is important for them to talk with their child/ren about the situation.
- Say that even though it is painful to have these conversations, it is important to do so.

We know it is important that parents and others keep children in the loop when someone close to them is dying. We know this helps children cope better after the person has died. Children who've been bereaved say that they are glad they were told what was happening.



Initiating the conversation

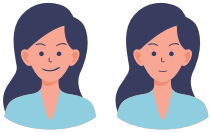
Non-verbal behaviour

Communication skills

- [ ] Facial expression
- [ ] Eye contact
- [ ] Open body language
- [ ] Pace, pitch, and tone
- [ ] Touch
- [ ] Space
- [ ] Maintain focus on the parent

Facial expression

- Be aware of your facial expression. At times in this conversation a warm expression will be appropriate; at others, a serious and engaged one.



Initiating the conversation

Eye contact

- Make and maintain appropriate eye contact.

Open body language

- How we position and move during conversations can convey strong messages. With parents, sit at their level and slightly open your posture.

TIP

Leaning forward at times can demonstrate interest. At other times, a relaxed posture can show you are listening attentively without rushing the other person. Try to keep aware of your body positioning and adjust if needed.

Initiating the conversation

Pace, pitch, and tone

- Use a gentle pitch, a slow pace, and a warm tone of voice.

Touch

- For some people, a touch on the hand or arm when they are upset can show support, care, and empathy; for others it may feel uncomfortable or intrusive. Take your lead from the parent as to whether and how much to provide touch. Be aware of any sensory issues/additional needs.

Space

- Give people physical space while staying connected.

Initiating the conversation

Maintain focus on the parent

- Relaxed, open non-verbal behaviour helps build rapport and trust. It can also model a calm, steady approach they may use with their child. Remember that non-verbals are ‘two-way’: observing the parent’s non-verbals helps you understand how they are feeling and how much they are taking in.

Gathering information

Assess the parent's understanding and what the child may already know

Communication skills

- [ ] Establish the parent's and family's understanding (starting point)
- [ ] Explore what the child has been told so far
- [ ] Demonstrate empathy
- [ ] Explain the purpose of the conversation
- [ ] Provide structure

- Finding out what is already known can help you judge whether they understand that the person may die, and what they believe is happening.
- Once you have established what they know and what they want to know more about, you can fit what you say to their starting point.

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Gathering information

Establish the parent's understanding

Just so I know where to begin, can you tell me what you understand about why [relative] is in hospital/so unwell?

What have you explained to [child's name] so far?

What words have you been using with them?

What do you think they understand about what is going on?

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Gathering information

Demonstrate empathy

I can hear this is really hard to talk about.

It sounds like you've been very worried.

It makes sense that you're unsure how to talk about this with [child's name]. Parents often feel that way.

Explain the purpose of the conversation

- Signpost your goals for the meeting.
- Restate their concerns and summarise a shared agenda.
- Make it clear that part of your role is to advise them on how to talk with their child.

I'll do my best to explain things clearly. If I say something that doesn't make sense, please stop me and I'll say it another way.

Providing information and planning

Provide the right amount and type of information

Communication skills

- Chunk and check
- Ask what other information would be useful
- Avoid giving advice or reassurance prematurely
- Specific advice for parents

Chunk and check

- Provide small chunks of information and allow time for this to sink in. Parents may respond with questions, silence, or strong emotion.

Providing information and planning

Ask what other information would be useful

Some people want to know what might happen next, or what it will be like when someone is dying, so they can prepare their children. Would that be helpful for us to talk about?

What are you most worried [child's name] might see or misunderstand?

Avoid giving advice or reassurance prematurely

- Avoid moving too quickly to reassurance or solutions (e.g. "*You'll be fine*", "*Don't worry*") as this can shut down questions and feelings.
- Allow time for difficult emotions to be expressed before moving into specific advice on how to talk with their children.

Providing information and planning

Advice for parents

The basics of communicating about the situation with children

- Telling children what is happening is helpful to them.
- Children who have experienced the death of someone close and who have been told what was happening often say they are pleased they were told.

TIP (for parents)

Be kind to yourself. You might think that if you get what you say just right, you can make things better. This way of thinking can put your communication under unnecessary pressure. Try to remind yourself that even though you wish you could make everything okay for your child, you cannot. This can help you to be calm and communicate more clearly.

Providing information and planning

Advice for parents

Timing

- Encourage parents to talk when they are not acutely distressed (if possible).
- It is okay for children to see sadness – this can model that feelings are normal and can be expressed.
- Suggest they think about whether a trusted friend or relative could be part of the conversation.
- Advise choosing times when there aren't other competing demands; conversations can sometimes feel easier while walking or travelling, not always face to face.
- If the topic comes up at bedtime, encourage parents to do something together afterwards (read a book, play a short game, or talk about something comforting) before leaving the child.

Providing information and planning

Advice for parents

Gather before you give

- Encourage parents to first find out what the child already knows and thinks.
- Ask them to listen for misunderstandings (e.g. "*cancer is catching*", "*it's my fault*").

Avoid interrupting

- Even if the child's words reveal misunderstandings, advise parents to let them finish before responding.

Avoid criticism; use supportive feedback

- Suggested responses: "*Mmm hmm*", "*I get it*", "*I know this is really hard to talk about*", "*Thank you for telling me that.*"

Tell children they can speak freely

- Examples to offer parents: "*Even though I'm really sad, what you say won't make it worse*", "*I'm not going to get cross about anything you say.*"

Providing information and planning

Advice for parents

Use the child's terms and language

- Encourage parents to use the same words their child uses ("*getting worse*", "*not here anymore*"), while gently checking whether the child really understands that the person is dying.

Use clear language and explain dying

- Encourage clear, simple words; avoid confusing euphemisms like "*gone to sleep*" unless they are explained.
- Suggested wording:

> *Your mum is very, very sick, and the doctors don't have any treatments or medicines that can make her better. It's different to when you go to the doctor with a sore throat and you get medicine. When someone is this sick, their body starts to slow down, they may not be able to talk or walk, but they may still be able to hear you.*

> *This means your mum's body will stop working, her heart will stop beating, she won't be able to breathe anymore, that is called dying.*

Providing information and planning

Advice for parents

Keep it short/afterwards

- Children often manage better with **several short conversations** rather than one long one.
- Advise parents to allow time afterwards to do something the child enjoys. Children need to continue to have fun, see friends, and go to school.
- Encourage parents to let school and other key adults know about the conversations.

What to say to help children talk

- Emphasise that asking questions is important, and how questions are worded matters.
- Encourage wording that invites a response.

Providing information and planning

Advice for parents

Useful sentence starters for parents:

- "*I wonder if…*"
- "*Could you…*" / "*Do you think you could…*"
- "*Is it okay if…*" / "*Would it be alright to…*" / "*Would you mind…*"
- "*When you're ready…*"
- "*I'd really like to hear…*"
- "*If you'd like, could you tell me…?*"
- "*Are you up for…?*"
- "*Could I ask you…?*"

Encourage questions that let the child raise the topic

- Broad questions: "*I wonder, have you been thinking about how Mum's doing?*"; "*Can you talk with me about what's happening to Mum?*"
- Ask about feelings: "*You know you've not been sleeping well – what do you think that's about?*"; "*What do you think when you see Daddy getting more and more tired?*"

Providing information and planning

Advice for parents

- Ask about causes: "*Have you thought about why Dad might be getting more and more sleepy?*"
- Pick up on earlier comments: "*You know the other day when you mentioned… Can I ask what got you thinking about that?*" then "*Did that make you think about what's going on for your Dad?*"
- Refer to others' comments: "*You know when Mummy/the doctor said… What did you think? How did that make you feel?*"

If needed, be more direct

- When necessary: "*I know it's really hard, and I need to talk with you about Mummy being really ill, and about what is going to happen in the future.*"

Providing information and planning

Advice for parents

Comforting and reassuring children

- Encourage parents to **show empathy** without claiming to fully understand. Only the child can truly know how they feel.

Non-verbal empathy:

- Soft, serious tone of voice.
- Physical closeness, leaning in, touch, hugs (if appropriate).

Verbal empathy:

- Mention how the child may be feeling.
- Ask about feelings; acknowledge them; reassure that these feelings are normal.

Providing information and planning

Advice for parents

Things children may think and say

- Explain that research shows children may think and react differently from adults.

Children may think they caused the illness

- Encourage parents to check gently and dispel this:
  - "*Sometimes children think they've caused the other person's illness or cancer.*"
  - Even if they deny it, it can help to say this and then clearly reassure them it is **not** their fault.

Children may show a wide range of reactions

- No visible emotion, intense distress, delayed distress, anger, or a mix – all can be normal. Encourage parents to accept and support however the child responds.

Providing information and planning

Advice for parents

Practical and blunt questions

- Prepare parents that children may ask very practical questions:
  - "*Will we still be able to live in our house?*"
  - "*When will they die?*"
  - "*Can I still do gymnastics?*"
- Advise answering as clearly as possible; where there is uncertainty, say so and promise to come back with information where possible.

Questions about time and prognosis

- Younger child:
  - *"That's a really important question. It is not possible to predict the exact timing; the team looking after your mam will let us know if they notice any changes."*
  - "*About your birthday, we hope she will still be here, and we can't promise that. What we can do is make sure you have special time with her now...*

...If it feels right, we could ask Mum if celebrating something together early – like having a cake or doing something you both enjoy – would be nice."

- Older child/young person:
  - *"I'm really glad you asked that question. It is not possible to know exactly when your mam will die. If the team looking after her are worried that time is very short, and when they notice any changes, they will let us know."*
  - *"So, when it comes to your birthday, I wish I could give you a definite answer. We don't know if she will still be here. Together with Mum, we can think about what would be important to both of you. Maybe we could have a small celebration with a cake, watch a movie here, or something else you choose."*

Providing information and planning

Advice for parents

When the parent's condition seems to change

- Younger child:
  - *"Your mum is still very sick and you know we can't make the illness go away. Today she seems a little better than she did yesterday. When someone is very sick, they can have days when they feel a bit stronger and days when they seem weaker. We don't always know when those changes will happen."*
  - *"What we do know is that the time you have with your mum is very special, so what might you like to do today with your mum?"*
- Older child/young adult:
  - *"So today she seems a bit better than she did yesterday. When someone is this unwell, it's common for them to change from day to day or even hour to hour...*

Providing information and planning

Advice for parents

...They can have times when they seem more alert, comfortable and able to talk with you, and other times when they are really weak, tired and sleepy.

– *We can't always predict when and how those changes will happen."*

– *"What this means is that, while we know she is going to die from this illness, we don't know exactly when. Because of that, let's do everything we can to spend time with her now."*

Providing information and planning

Aid recall and understanding

Communication skills

- Use easy to understand language
- Organise the explanation
- Keep a steady, slow pace
- Pause often
- Check understanding
- Demonstrate empathy
- When the time feels right, suggest moving on to the next stage

TIP

If a parent becomes distressed, you may notice longer pauses, less eye contact, changes in voice or crying. Give time. Simple phrases such as "*It's okay to be upset; take your time*" are often helpful. When the time feels right, you can suggest moving to the next topic.

Providing information and planning

Incorporate their perspective (I.C.E. and G.I.V.E.)

Communication skills

- Use I.C.E. (Ideas, Concerns, Expectations)
- G.I.V.E. to connect, understand and support

Use I.C.E. (Ideas, Concerns, Expectations)

- Ask what is important to the parent and to the child now.
- Examples:

What worries you most about what is happening – for you, and for [child's name]?

What do you hope will happen over the next few days or weeks, especially for your children?

- Where appropriate:

What would your [relative] say is most important to them as they come towards the end of life? For example, who they would like to have with them, or where they would like to be?

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Providing information and planning

G.I.V.E. to connect, understand and support

G – Get the emotion

- Notice when the parent is showing feelings through words, silence, and non verbals.

I – Identify the emotion

You seem quieter than before. I'm guessing this might be really hard for you. Would you like to take a break for a bit?

V – Validate by acknowledging feelings

This is really hard; parents often feel scared or angry when someone they love is very ill and they're trying to protect their children.

E – Explore to better understand the emotion

Tell me more about what you're most worried about – for yourself, for [child's name], or for your [relative].

I gave you a lot of information. What questions do you have for me now?

Providing information and planning

Shared planning and support

Communication skills

- Share your thinking
- Explore options
- Negotiate the plan
- Check with the family

Share your thinking and explore options

- Using "*we*" can remind everyone that this is a team effort and that the family is not alone.
- Explore with parents what they feel able to say to their child, and where they would like support (for example, practising words, having you nearby, or you joining part of the conversation).

Providing information and planning

Negotiate the plan with the parent

- Explain clearly what is and is not possible.
- Consider timeframes explicitly: when appropriate, be clear with parents if you are thinking in terms of "*days rather than weeks*" and explore what this means for how and when to talk to the child, and for how they might want to spend time and say goodbye.

Closing the conversation

Ensure an appropriate point of closure

Communication skills

- ☐ Summarise the conversation (briefly)
- ☐ Check with the parent
- ☐ Outline next steps

Summarise the conversation (briefly)

- Briefly summarise what was discussed in clear, simple language.

So, I've given you quite a lot of advice on how to talk with your child/children. We don't expect you to remember all of it. Here's a sheet with all that advice on it. Feel free to share it with other people in your life.

Closing the conversation

Check with the parent

- Allow them to correct or add information.
- Use simple screening questions, for example:

Is there anything you were wondering about that I haven't talked about yet?

Was there anything I said that didn't make sense, or that you're not sure how to explain to [child's name]?

Closing the conversation

Forward planning

Outline next steps

- Explain what will happen next and who will keep in touch.
- Encourage use of available resources (school, community, faith and voluntary services).
- Emphasise that the family is not alone, including in talking with children.
- Discuss how best to support the family.

Example wording:

I'm going to talk to the rest of the team and I'll write down what we discussed in the notes, so that everyone knows what we talked about. We will make sure we update you if anything changes. We'll check in with you again tomorrow/next week, and you can ask to speak with us sooner if you need to or have any questions.

End-of-Life Conversations

GUIDING PARENTS TO PREPARE CHILDREN/YOUNG PEOPLE WHEN SOMEONE CLOSE IS DYING

Self-care for families and staff

To the adults:

This is very hard on you. You may not feel like thinking about yourself, but looking after yourself – even in small ways, like eating, resting or getting some fresh air – will also help you support [child's name]. It's okay to ask for help.

For staff:

Supporting parents and caregivers to talk with their children about dying and death can be emotionally demanding. Seek supervision, debriefing, and team support after these conversations. It is appropriate to say something like, "*I'm going to step out for a few minutes, get some air, and then I'll come back. These conversations are a lot for everyone.*" Modelling healthy self care can also help families feel permission to look after themselves.

This Skills Card is the work of the National Healthcare Communication Programme.