

Talking about deteriorating health, dying and ‘what matters’

A communication guide for professionals
about care planning

Overview

When caring for people with deteriorating health due to one or more advanced illnesses, professionals need to be ready to start conversations about the risks of deteriorating and dying, what matters most to that individual, and how we can plan future care together.

We talk about what people know and expect, accept uncertainty, acknowledge variable 'prognostic awareness', share information sensitively and effectively, respect different ways of coping, explore people's hopes and priorities, and discuss individualised treatment and care options.

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'It is much more important to know what sort of patient has a disease, than what sort of diseases a patient has.'

'Medicine is a science of uncertainty and an art of probability.'

Sir William Osler

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This Guide includes evidence-informed approaches to talking about deteriorating health. Key steps in having an effective conversation are outlined with some examples. These are suggestions that must be individualised, used appropriately and in the right context.

Acknowledgements

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'If we talk about 'future care planning' that means I have a future and something to hope for.'
Service user representative

Part 1: Effective communication about deteriorating health

Identifying people at risk

- Three main groups of people should be identified and encouraged to have conversations with health and care professionals about deteriorating health and planning future care.

1. People at risk of deteriorating health in the future

- One or more advanced/ life-limiting, long term conditions.
- Physical and/ or mental health problems that are likely to deteriorate in the future.
- New diagnosis of a serious illness.

2. People whose health is unstable or deteriorating with one or more advanced conditions

To help you identify these people use SPICT™ (www.spict.org.uk) and look for:

General indicators of deteriorating health:

- Performance status is poor or deteriorating with limited reversibility.
- Depends on others for care due to physical and/ or mental illness.
- Unplanned hospital admissions.
- Significant weight loss over the last few months or remains underweight..
- Persistent symptoms despite optimal treatment of underlying conditions.
- Person asks for palliative care or to reduce/stop treatments; focus is on quality of life.

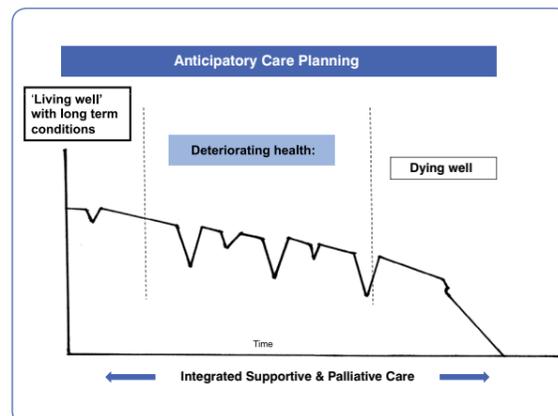
Clinical indicators of one or multiple advanced conditions (multimorbidity) including:

- Cancer; advanced heart, lung, liver or kidney disease; advanced neurological conditions; frailty; dementia; other life-limiting conditions.

3. People who are dying (*in the last weeks to days of life*) or at high risk of dying soon

- People dying with one or more advanced, progressive, incurable conditions.
- People with a life-threatening complication or a severe exacerbation of an advanced, progressive condition.
- People with life-threatening, acute conditions with little or no reversibility.

- We talk about the person’s health problems, their hopes and priorities, and planning ahead.
- Involve family members and others close to the person unless the person chooses not to do this.
- It is important to avoid ‘*prognostic paralysis*’ caused by waiting until it is certain that a person will deteriorate and die – those ‘at risk’ of deteriorating should be assessed for unmet needs and offered opportunities to talk about their health problems and priorities.
- An acute event or a change in health status may ‘trigger’ a discussion but it is better to initiate care planning reviews when the person is more stable.



Being ready for conversations about deteriorating health

When

- Look for opportunities to have these conversations:
 - When discussing future care with someone who has a new diagnosis of a life-limiting condition and when a person’s capacity will be impaired in the future (eg. dementia).
 - When someone asks about a Power of Attorney (proxy decision-maker).
 - During a planned outpatient clinic review or GP practice appointment.
 - After an unplanned hospital admission.
 - When a treatment plan is changed or options for treatment are reviewed.
- Conversations about deteriorating health and planning future care are part of an ongoing process of communication, not a ‘one-off’ discussion.
- Many illness trajectories follow an unpredictable, uncertain course and people’s priorities and choices change over time. Timely review of all care planning is essential.

Who

- Arranging a planned discussion (even in an acute situation) lets everyone, including the person, prepare. It helps make sure the right people are involved.
 - *When someone has been in hospital with these problems, we plan a discussion to talk about their health problems and how we can care for them as well as possible in future.*
 - *We need to make some decisions about the best treatment for your (health problem), so can we plan to talk about that this afternoon?*
 - *People often have a family member or close friend join us. Would you like that?*

Assessing decision-making capacity

- Decide if the person can: understand enough information about an option or choice and its outcomes, remember the information, use it to make a decision, and communicate it.
 - Have you made every effort you can to help them to do this?
- People may be able to make choices about some things while lacking capacity for more complex decisions.
- If a person’s decision-making capacity for any of the decisions to be made is impaired:
 - Professionals will need to make a decision that will be of most benefit to the person. When making decisions, involve those close to the person and ask them about what the person’s views might be.
 - If there is an Attorney with health/welfare powers, always involve them. All decisions that are made must be of most benefit to the person.

What

- Decide what information is needed and make sure it is available in the right formats.
- Check for any information about previous discussions or plans.
- Be prepared to share ‘bad news’ and respond to sadness, distress, anger, guilt, and other emotions. (See: Emotional responses to facing loss, death and dying; page 7)

How – key points

- Always take account of people’s awareness of their current health and prognosis, and their readiness to talk about deteriorating health.
- Be prepared to help people with unrealistic or uninformed expectations. We need to explain why some treatments are not available, do not work or may have little benefit/ poor outcomes.
- Be ready to address diverse needs and ways of coping within a family.
- Acknowledge uncertainty honestly, and offer support in managing it (See page 5).

- Some people have thought ahead and can be specific about the things they would like or do not want, but many have not. Even people who have planned ahead may have done this in ‘abstract’ so still find the real situation distressing.
- **Many people want to focus on living as well as possible from day to day.** They do this by trying to carry on with normal life as much as possible, and not thinking about ‘*planning for dying*’. We must strike a balance between helping people be more open while respecting a clear choice not to plan ahead if they are relatively stable.
- People are only able to think about and plan for situations that mean something to them personally. They need individualised information shared with them about what is happening with their health before they can think and talk about planning ahead.
- Ask about ‘*what matters*’ to each person and ‘*what we need to know about them to care for them well*’. This informs discussions about possible options for treatment and care.
- People’s priorities are shaped by values, ideas, beliefs, fears and experiences. Some find naming specific goals hard, but can talk about what is important to them in general.
- Talking about things they would like to do or go on doing, what they hope for and what makes life worthwhile helps people continue to hope for important things that can happen.

Sensitive and effective conversations

- Make sure people know your name and role, and you know theirs.
- Build a relationship by finding out about this individual person.
- People value responses like ‘*Can I help?*’ or ‘*Can I find out for you?*’.
- Non-verbal ways of showing concern have a big impact (tone, touch, kindness).
- Clear, simple concepts and language are important when people are distressed. Share small **chunks** of information, then **pause** or **check** for the response.
- Making a link to recent changes/ events can help open up a conversation if the person is not aware of how ill they are:
 - o *What has changed since you went/ came into the hospital?*
 - o *You need more help at home now; can we talk about why that is?*
- Making questions less direct and personal helps open up conversations in a gentle way:
 - o *Sometimes people choose someone to help make decisions for them if they get less well, have you thought about that?*
 - o *If you got less well again, what do you think about going back into hospital?*
- Linking shared hopes with our concerns can help people to cope with being more open:
 - o *I hope you will stay well for a long time, but I am worried that you will have another of those times when you get much worse... Can we talk about that?*
- Acknowledging emotions and sharing wishes that things were different helps people cope with sadness and loss:
 - o *I wish we could give you more treatment... Can we talk about what we can do if that’s not possible?*
- People often swing between hoping for the best and being more open. Help the person have more control by checking when they feel they have talked enough:
 - o *We want to keep positive and focus on what we can do, but can we talk about making some plans ‘just in case’?*
 - o *You can decide how much we go into that, and also when we’ve talked enough.*
- Refer to: Potential problems in discussing future treatment and care options. (page 8)

| Talking about ‘what matters’ and planning ahead: key steps | | |
|--|--|---|
| RED-MAP | | |
| Ready | Can we talk about your health and care? | When would be a good time to talk? Who should join us? |
| Expect | What do you know? What do you want to ask? What are you expecting...? | How have you been doing recently? What has changed? How do you see things going now...? Do you have questions or worries you’d like us to talk about? Some people think about what might happen if...? |
| Diagnosis | We know... We don’t know... Any questions? | What is happening with your (health problem) is... We hope that..., but we are worried about... It is possible that you might not get better because... We don’t know exactly... can we talk about that? |
| Matters | What matters to you now? | What’s important to you that we should know about? Are there things you’d like or wouldn’t want for you? |
| Actions | What can help... This will not work... | Some things we can do are... This treatment will not work for you / not help you because... |
| Plan | Let’s plan ahead for when/if... | Can we make some plans so everyone knows what to do? Talking and planning ahead ‘just in case’ helps people get better care. |

Discussing uncertainty and responding to ‘difficult’ questions

- Find out what the person already knows, what they want to know now, and why they are asking a question before responding.
- A pause and ‘reflecting back’ the question softens the response and helps us answer clearly, but gently. Acknowledge uncertainty and talk about how we can hope and plan.

What are the ‘chances’ of the treatment working?

- *I’m not sure if the (treatment) will help...we’ll have a better idea in...*
- *We are as certain as we can be that your (condition) means that...*
- *I think you might not get better this time.... Can we talk about that?*

‘How long have I got?’

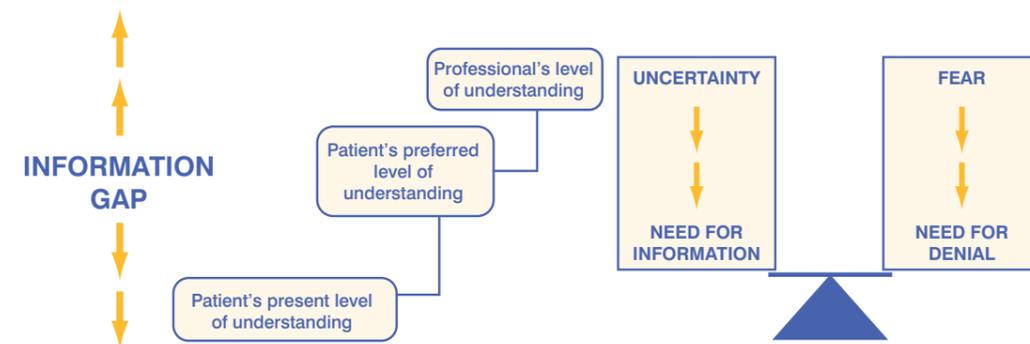
- *No one can tell you for certain how much time you have, but I am worried that you are much less well than you were when..., because...*
- *I think we are probably looking at days to weeks/ weeks to months/ months to years. We are likely to have a better idea as time goes on and we see how you are.*
- *Can we talk about what is most important for you now, and how we might cope with not knowing exactly what will happen and when?*

‘Am I going to die?’ ‘Should we call the family?’

- *Can I ask what makes you think that that you might be dying....?*
- *I am not expecting you to die in the next few days but you are very unwell. It is possible you could get more unwell at any time – if time is short, what would be important for you?*
- *We are looking at a short time... I think that he/she is likely to die quite soon...*

Breaking bad news (eg. SPIKES approach)

When sharing difficult, complex and potentially distressing information make sure everyone is prepared. The professional needs to find out what the person already knows and what they want to know before giving information and as the information is being shared.



Set up the interview – place, those present, resources, arrangement of chairs in a room.
 Perceptions of the patient/ relative – find out what they know already.
 Invitation to give the information – warning shot first if they have little idea, then PAUSE.
 Knowledge – share the information in chunks with checks for understanding and impact.
 Emotions – dealing with the impact by eliciting, prioritising and summarising concerns.
 Strategy – look at the options and agree an action plan.

Receiving difficult information:

- Existing worries are confirmed and/or new concerns raised.
- If the professional gives more information and/or reassurance to lessen anxiety and distress, the person may:
 - become pre-occupied with their concerns.
 - fail to take in any more information or reassurance.
 - focus on negative outcomes (death, disability, loss of capacity).
- Distress can be lessened and information given more effectively if:
 - distress is acknowledged and the person's main concerns and feelings are explored.
 - the person's own solutions are explored first, and then they are asked how the professional can help. *What could help you with that? How can we help?*
 - the specific information needs that have been identified are addressed.

Sharing difficult information – key points

- If possible, ask in advance if the person would like a family member or friend present.
- Ask about what they know and understand already; assess their information needs.
- If there is some good news, give this first (*You have recovered well from surgery, but...*)
- Give a suitable warning shot if they have little or no idea about the situation.
- Share the information clearly and sensitively - in small chunks, with pauses.
- Help prioritise concerns and questions; then discuss key issues and possible actions.
- Offer advice, reassurance and support; including how to share the information with others.
- Summarise the interview and agree a shared action plan.
- Safety net: check it is safe to end the interview; make follow-up arrangements.

Emotional responses to facing loss, death and dying

These reactions often change and vary over time. People may have different responses from those who are close to them or within a family. Start by listening to their story and respond appropriately - do they talk about the facts, their feelings or what they have tried to do? Seek advice and support early if emotional responses are strong or complex.

- Distress / grief** (*I'm crying, it's so sad, it's too upsetting to face.*)
 - Listen; respond in an empathetic way; ask about what matters most and what could help with those things.
- Sadness/ withdrawal** (*What's the point...*)
 - Listen; offer support; invite the person to talk about what matters. Screen for depression if the person has persistent low mood and is unable to find enjoyment in living.
- Collusion** (*Don't tell..., it will be too distressing/ he will give up...*)
 - Find out why they are protecting someone. Some people try to be positive and have a 'fighting spirit' to avoid disappointing or letting down family members or professionals. Explore the disadvantages and benefits of being more open about what is happening. Negotiate finding out what the other person actually knows and wants to know.
- Guilt** (*If only I had got him to see the GP...*)
 - Listen in a non-judgemental way; negotiate looking at the things we can do now.
 - This may be expressed as anger or complaints about care if the person has not been able to support the patient well or their relationship is complex.
- Anger/ blame** (*It is the GP's fault.../ If you had treated him properly...*)
 - Listen, acknowledge and apologise for the distress experienced and for any errors; try to negotiate a way forward that would help the person who is dying and/or the situation of the person who is complaining, now or in future.
- Bargaining** (*You might have made a mistake..? Can we decide about that tomorrow?*)
 - Acknowledge the person's reasons for wishing things were different; explore the person's understanding of why we are as certain as we can be about the situation.
- Denial** (*It can't be true.../ I don't want to believe it...*)
 - Acknowledge the difficulty of the situation, explore their understanding, and gently explore inconsistencies in the account, and their willingness to be more open.
- Focus on negative outcomes** (*death, disability, loss of capacity*)
 - Explore the person's reasons, beliefs, values and fears; try to find 'common ground'.
- Different ways of coping** (*You may be angry, but I just feel overwhelmed...*)
 - Involve everyone in the discussion; respond to different emotions and concerns.
- Fighting spirit** (*We must carry on with treatment...*)
 - Explore the person's reasons, beliefs, values and fears; try to find 'common ground'.
- Acceptance** (*It's going to happen, so what matters now is...*)
- Living well now** (*I want to take it a day at a time, but I know things will change at some point*)
 - Respect what can be a helpful way of coping if things are stable. Acknowledge the difficulty of thinking too much about the future. Talk about the benefits of being positive and focusing on the present. Negotiate starting to plan ahead 'just in case' at the same time.

Potential problems in discussing treatment and care options

- ✗ DO NOT focus on a treatment decision or on completing a form or plan without first discussing it in context. People are not able to participate in discussions about treatments (eg CPR) unless we have already been talking about deteriorating health, risk of dying or making choices in advance of losing decision-making capacity.
- ✗ AVOID euphemisms, a mixture of positive and negative messages, and long, vague explanations that lead to confusion or misunderstanding.
 - ✗ *You are a bit more ‘poorly’ but we have good treatments for your condition.*
- ✗ AVOID negative language: ‘futile intervention’ or ‘treatment withdrawal’ can mean the person is not valued or is being abandoned; ‘ceiling of care’ means being denied treatment; being ‘made palliative’ means being left to die.
 - ✓ DO talk about what will help/ what we can do.
- ✗ AVOID asking the person or family if they want us ‘to try’ a treatment (eg CPR, clinically assisted nutrition or renal replacement therapy). Some people think ‘not trying’ is the same as ‘giving up’. The response is often, ‘Yes, we want you to try’.
- ✗ AVOID talking about the ‘chances’ of a treatment working as this can lead to people feeling that they should take ‘any chance’.
 - ✓ DO offer factual information about why a treatment will not work, or have a poor or uncertain outcome for this person.
- ✗ DO NOT ask family members to make the decision about CPR or any other treatments for their relative.
 - ✓ DO ask the person’s registered welfare attorney(s) to be part of shared decision-making about treatment options in line with the powers listed in the POA document.
 - ✓ DO involve those close to the patient and talk with them about what is happening. Ask them if they can tell us about what **would be important** to this person.
- ✗ AVOID saying ‘the professional team have decided’ about a treatment/ care plan as people can feel excluded and belittled. Shared decision-making means talking about why options will not work or be of low benefit.
- ✗ DO NOT start to talk about the possibility of dying, and then immediately offer premature reassurance about the good care we can give a dying person – it can cause more distress.
 - ✗ *You are getting worse, but we will do all we can to keep you comfortable...*
- ✗ DO NOT talk about getting a CPR form or care plan ‘signed’. This makes people think the document is a consent form to be signed by the person or their next of kin/ attorney. The focus should be on sensitive and effective communication, and not on completing a form.

Some people have prolongation of life and survival as their main priority.

- ✗ AVOID focusing on the ‘futility’ of a treatment or how unpleasant/ harmful it might be as this is seen as reluctance to help or denial of rights..
 - ✓ DO TRY to ‘reach common ground’ by finding out about their reasons, priorities, beliefs, concerns and fears; and then look for an agreed ‘best way forward’.
 - ✓ DO seek a second opinion (eg. from a senior colleague and/ or a palliative care specialist).

Shared decision-making

- Sharing decisions is a key requirement of person-centred care and realistic medicine.
- Increases satisfaction with care and people’s confidence in treatment / care decisions while reducing complaints and regrets.
- Involves shared responsibility, using evidence well and thinking together about available options tailored to the person’s situation and wishes.
- Informed consent depends on effective shared decision-making discussions.
 - Consent is valid if: the person understands they have a choice to make, what might happen, and they can remember and use the information we have given them to reach a decision.
 - Always check what the person has understood by asking them to tell you.
 - We must talk about any risks that could be considered important by a person in this situation (a legal requirement).
- Patients and family members cannot demand a treatment or intervention that is contraindicated or illegal, or one that would not have a medically successful outcome. We explain why some treatments will not work, or are unavailable, or why outcomes are poor for a person like this.
- Only the patient or a legally-appointed, proxy decision-maker (eg a welfare Attorney in Scotland) can consent to a treatment. If the person lacks capacity to make decisions, has not made a valid advance directive, and has no proxy, the professionals responsible for the person’s care need to make decisions that are of overall benefit to the person and take account of any available information about the person’s likely views.

Shared decision-making with a person whose health is deteriorating

- Build a relationship of trust and encourage participation and partnership.
- Check what everyone knows and understands about the situation and any decisions to be made. We discuss what we can do and the best options available for this person.
- Find out how much information is needed and think about how best to present it.
- Clarify the roles and responsibilities of patient, family (including any welfare Attorney/ proxy decision-maker) and the professionals.
- Find out about what is most important for this person at this time and in the future?
- Provide tailored information applicable to this individual:

Remember Chunks + Checks with Pauses

- Discuss the available options, including not having more tests/ treatment, or deciding later.
- Discuss the benefits and possible risks of the options and how likely they are.
- Check everyone’s understanding and address any further questions/concerns.
- If the person lacks capacity for this decision, ask about their likely views and talk about which option(s) would be of greatest overall benefit to them.
- Agree a decision and a clear action plan; offer further resources/ information
- Before closing, summarise the discussion and plans, check their understanding and if there are more questions or worries; make follow-up arrangements.

Part 2: Discussing future care planning

People at risk of deteriorating in the future

(Early anticipatory care planning or advance care planning)

Starting these conversations early and continuing them over time is important. We are planning for 'if' or 'when' the person deteriorates and/ or loses decision-making capacity.

(Group 1: page 2)

Find out what the patient and family are thinking, and 'what matters' to them.

Open up a conversation by making a link to a recent change in health or care needs.

- How have you **been doing** recently? What happened in the hospital?
- What do you **know** about your health problems?
- What do you **think might happen** with your (health problems) in the future?
- Do you have any **worries** or **questions** you'd like us to talk about?
- What things are **important** for us to know about you....?
- What would help with that? How can we help?

Introduce the topic of planning ahead as a 'general concern'

Sometimes people think about what might happen if they were less well in the future.....

How do you feel about that? Is that something you'd like to talk about?

We offer everyone like you a time to talk about what might happen with their health in future. It is better for us to do that when people are well and can think about what is important for them.

If the person's condition is stable and they choose not to talk about their future care, respect this and raise the topic again if the situation changes.

Power of Attorney

- Sometimes people want to choose two or more family members or close friends to make decisions for them if they get less well in the future. The decisions can be about things like managing money or property or about treatment and care.
 - Have you ever thought about that?
- If you couldn't talk to your doctors and other professionals about your treatments and care or what is important to you, would you want someone you trust to be able speak for you?
 - Have you talked with your family/ close friends about that?

Legally appointed, proxy decision-makers (with a Power of Attorney) need support and preparation for their role. They must always act for the overall benefit of the person.

Advance decisions about treatment

- *I/we hope you will be fine for a long time but, if you did get less well, do you have any thoughts about what you would like to happen that we should know about?*

Some people may want to specify certain treatments they would not want in future such as CPR, ITU admission, ventilation or clinically-assisted nutrition.

- *Some people have strong views about treatments that they would NOT want to have in the future....Is that something that's important for you?*
- *A treatment that some people want to think about in advance is something called CPR or cardiopulmonary resuscitation. Is that something you'd like us to talk about?*

Talk about any other questions or concerns.

Discuss recording and sharing the person's advance care plan.

- *We will make a record of any plans we make together so that the people looking after you know about them. We can update the plan at any time you want to do that, or if things change.*

Anticipatory care planning with people whose health is unstable or deteriorating

This means making plans for what we will do when a person's health deteriorates. It includes an emergency care and treatment plan in case the situation changes rapidly. (Group 2: page 2)

Find out what the patient/ family are thinking and expecting; summarise what is said.

- Is the person aware that their health is deteriorating?
- Are they ready to talk about the fact that they might deteriorate further and could die?
 - How have you **been doing** recently?
 - How have you **been** since coming into/ out of hospital this time?
 - Can you tell me what you **know** about your health problems?
 - Do you have **any questions** about what you've been told already?
 - Can I ask what you are **expecting** to happen?

Share information tailored to this person and linked to their understanding.

If the person is not at high risk of deteriorating/ dying very soon and they are very ambivalent or unaware of their situation, have this conversation gradually on several occasions.

- Talk through recent experiences to help the person see how and why they are less well.
 - *How were things left with the cancer clinic doctor/ your oncologist/ the specialist?*
 - *I'm worried that your (health problem) is starting to cause more problems because.....*
 - *This would be a big operation/ strong treatment even in a fit person... because of your (health problem), we are worried it might make things worse.*
- Give clear, factual information in short chunks with pauses for the person to respond.
 - *Can I just check if you want us to talk about what I've told you so far?*
- Give a warning about deteriorating health and check their readiness to talk about the future.
 - *The (treatment) has helped this time and I am glad you are feeling a bit better but, **I am worried** that at some stage you will get more unwell again.*
 - *Is that something you have thought about?*
 - *It can be a good idea to plan ahead for what we might do if you get less well.*
 - *What would be the best way for us to talk about that?*

Focus on what matters most to this person.

- Before we talk about how we can make some plans for your care, can I ask you:
 - What things are **important** to you that we should know about?
 - When you think about the future, what **matters most** to you?
 - What **could help** with that? How can we help? What we can do is...

Talk about options; agree an anticipatory care plan and when to review it.

- The options for treatment and care will depend on the person's priorities, current and likely future health problems, family situation, and their preferences about place of care.
- Find out if they have a POA in place and if there are specific things they'd like or would not want. (See: page 10)
- Talk about making plans 'just in case' the person's health changes or they need more help.
- Discuss CPR as a treatment with a poor or uncertain outcome. (See: page 15)
- Handle uncertainty and 'difficult' questions with honesty and realistic hope. (See: page 5)

Talk about recording and sharing the person's anticipatory care plan.

Planning good care of people who are dying

Planning care of people who are dying (in the last days of life) or at high risk of dying soon means talking about what happens and how we care for people well. (Group 3: page 2)

- Thinking about dying as a reality that will happen in the foreseeable future can be difficult and upsetting. A series of conversations may be easier but that is not always possible if the person is deteriorating rapidly.
- Exploring the person’s concerns and what they think would help is much better than offering ‘unrealistic’ hope or ‘premature’ reassurance.
- **We need to be able to tell people that they are dying in a timely but sensitive way so that they have an opportunity to sort out the things that are important to them.**

Find out what the patient and family are thinking; summarise and check their understanding.

Is the person aware and ready for a conversation about dying, or unaware and ambivalent? This affects how difficult it may be for them to receive this information.

- *How have you (patient) **been doing** recently/ since coming into/ out of hospital...?*
- *It helps if you can tell me what you **know** about what is happening?*
- *What are you **expecting** to happen now?*

Share ‘bad news’ if the person is not aware of the situation, or confirm their understanding.

Give a warning and check their readiness for bad news.

- *I’m a bit worried that you are not getting better the way we hoped you would....*
- *We **hope** the (treatment) will help, but I **am worried** that at some stage, maybe even soon, you will not get better....*
 - *Is that something you have thought about?*

Exchange clear information in short chunks with PAUSES for the person to respond:

- *We are doing our best to treat your (condition) but there are times when the treatment no longer works because... You would not survive such a big operation... The specialist(s) looked in detail at all your test results and said that treatment with Z would not work.*
- *I’m sorry, but if your (condition) does get worse, then it is possible you could die.*
 - *We don’t know for certain when that might happen, but it is a possibility....*
 - *It is hard to say exactly but it might be in Sometimes things can change quickly...*
 - *That’s why it is important to talk about what we would do if that were to happen.*
- *I’m afraid that your (condition) is getting worse....*
 - *The (treatment) is not helping any more because the (lungs, kidneys etc) are failing...*
 - *I think you are not going to get better this time...*

Respond to distress with empathy

- *This is a very difficult/ sad time for you....This is hard for you...*

Focus on what matters most to this person and those close to them.

- *Can I ask what things are **important** for you now that we should know about?*
 - *What could help with that? How can we help?*
- *Do you have any worries or thoughts you’d like us to talk about just now?*

Discuss treatment and care in the last days of life.

Explain what happens when someone dies and why CPR does not work. (See: page 14)

Information leaflet ‘What happens when someone is dying?’ can be helpful. (See: page 16)

Part 3: Talking about cardiopulmonary resuscitation (CPR)

Guidance on communication and decision-making about CPR

DNACPR discussions are part of a series of conversations that start with the person’s understanding of their current condition and what is likely to happen as they get more unwell.

People say they prefer a series of conversations about CPR, being prepared for decisions in advance, avoiding discussions in a ‘crisis’, discussions involving family members, and discussions with a trusted professional.

A senior clinician (in discussion with the multi-disciplinary team) makes an assessment of:

- The person’s risk of a cardiorespiratory arrest.
- The likely outcome of CPR in this person.
- The capacity of the person to participate in discussions and decision-making about CPR.
- The validity of any advance decision refusing CPR.
- Whether there is a legally-appointed, proxy decision-maker.

A. The person is dying = CPR is contraindicated.

- A senior clinician (with their team) decides CPR will not be given, explains why this is, and documents the discussion. A DNA CPR form and/ or emergency care and treatment plan is normally completed.
- If a patient has a cardiorespiratory arrest and there is no DNA CPR form or recorded to the person (if able and wishes that) and their family, any health professional is able to make a careful assessment and decide not to start CPR, or to stop CPR.

B. The person has advanced illness and deteriorating health such that CPR does not work.

- A senior clinician (with the team) decides in advance not to give CPR, explains this decision to the person and their family, and documents the discussion.
- A DNA CPR form and/ or emergency care and treatment plan is normally completed.

C. CPR is a treatment option with a poor or uncertain outcome.

Decide who will be involved in the discussion:

- If the person has capacity to share in decision-making about CPR, support and involve them.
- If the person lacks capacity:
 - A welfare Attorney (proxy decision-maker) authorised to do so takes part in shared decision-making.
 - A senior clinician (with their team) makes a decision that will be of overall benefit to the person, having asked those close to the person what they know about the person’s likely views.

Consider and discuss the likely outcomes of CPR for this person taking account of their current and preferred place of care. Reach a shared decision.

Key points:

- * Professionals and proxy decision-makers must make decisions that are of overall benefit to the person.
- * Professionals are not required to give treatments that will not be of benefit. If there is disagreement about a treatment plan, seek a second opinion.

What is happening with the person’s health, and their treatment and care plan is always discussed with the person (if they are able and want to do that). The people close to the person and any registered Attorney are involved in these discussions unless the person refuses.

Talking about CPR when a person is dying (in the last weeks to days of life)

Talk about what is likely to happen in clear language that is easy to understand.

- *Can I ask if you know about what happens when someone is dying and how we care for them?*
- *Can I ask what you are expecting to happen...?*
- *What things are important for you and (person's name)?*
- *Do you have any worries you'd like us to talk about?*
- *You/ he/ she is likely to get more unwell (say how and why) over (time frame)....*
- *This is likely to happen gradually, but sometimes people die more quickly than we expect... Some people can stay the same for a while – or even improve for a short time - then get worse again.*

Explain that the heart and breathing will stop. PAUSE

- *When people get very ill and are dying, they are unconscious and then their heart and breathing stop.*

Explain that we are not able to restart a person's heart when they are dying. PAUSE

- *When that happens, we are not able to start the heart or breathing again.*
- *Treatments like cardiopulmonary resuscitation (CPR) do not work, so we focus on good care and allow the person to die naturally.*

Talk about sharing and documenting the care plan so everyone knows about it.

- *We write down/ record information about CPR when someone is very ill and dying. This way we can make sure everyone knows what is happening and what to do.*

Talk about how we care for someone who is dying.

- Helping the person with small amounts of food and sips of drinks, if they want them
- Good care of mouth and skin
- Symptom control, treatment and medication, including 'just in case' medicines
- Family care and support
- Spiritual, religious, cultural care
- Legal/ financial concerns

If the person is dying at home, talk about what to do when the person dies.

- *When people are at home, they keep their care plan and any document with the decision about CPR in a place that is easy to find.*
- *If (person's name) becomes very unwell or dies, phone your doctor's surgery. If the surgery is closed, contact NHS 24/ NHS Direct (out-of-hours doctor service). If you need help urgently, you can phone the emergency ambulance service and ask them for help.*

Resources

Information leaflet: 'What happens when someone is dying?' (See: page 16)

Scottish Palliative Care Guideline: Care in the last days of life. (See: Resources, page 20)

Talking about CPR and other treatments with poor or uncertain outcomes

Begin by asking what the person (and those close to them) knows about their health problems and is expecting. Then talk about why they are deteriorating and at risk of dying. Ask about what is important to them before talking about specific treatments.

Find out what the person knows about CPR.

- *I'm afraid it's possible, your (condition/ health) could get worse because....*
- *It is hard to talk about getting less well, but I worry that if we don't do that we will not be able to make good decisions about your care.*
 - *What would be the best way for us to talk about these things?*
 - *Is there a family member or friend we should be talking to as well?*
- *A treatment we talk about with everyone (unless they do not want to do that) is something called cardiopulmonary resuscitation or CPR...*
 - *Can you just tell me what you know or have been told before about CPR?*
- *If you think that you would not want CPR, it is important for everyone looking after you to know that.*
- *CPR is a treatment that can be used to restart the heart and breathing in some situations.*
- *In some situations it can work, but in other people (make a link to the person's health problems and understanding) it does not work well or work at all.*
- *If we think that CPR will not work well or not work at all, it is important to talk about that.*
 - *When people get very ill and are dying, the heart and breathing stop. When that happens, CPR does not work.*
 - *Some people have health problems that mean a treatment like CPR will not work or leave them in very poor health.*
 - *In your case, because... we think CPR would not work/ would have a very poor outcome. That's why we think it should not be used.*

Some ways to offer more information about the outcomes of CPR, if wanted.

- *We know that only about 5% of people in hospital (fewer at home or in a care home) with an advanced illness will survive when their heart and breathing stops and we give them CPR. Many will not be well enough to leave hospital and those who do get home usually have very poor health.*
- *About 18% of patients with long term health problems will survive if their heart or breathing stops and we give them CPR, but 30-50% of them will not recover fully.*
- *Can I ask what you think might happen if we gave CPR to someone with health problems like yours/ these?*

Discuss making an advance decision not to give CPR.

- *It is important to plan what we will do in advance to make sure every person gets the right treatment and care.*
- *Sometimes a person's health can change quickly and there may not be time to plan their care so we usually try to make decisions about CPR in advance.*

Talk about why we record and share the care plan.

- *So that everyone knows what to do, we make a record of the decision that CPR will not be used along with the other plans we make about care for each of our patients.*
- *What we decide about CPR does not affect any other treatments or care. The decision we make not to give CPR is only about that treatment and not about any other treatments or care for that person.*
- *When people are at home, they keep their care plan and any document with the decision about CPR in a place that is easy to find.*

Information for patients and families

What happens when someone is dying?

This leaflet aims to answer some of the questions you may have about the changes that often happen when someone is close to death.

Everyone is different, but in most cases there are common signs and changes that show us a person may be close to death. Sometimes people die very quickly. Others get gradually less well over several days or even longer. A few people look as if they may be dying but their condition then improves again for a while.

Please ask the people who are looking after your relative or friend if you need more help or have any questions.

1. Less need for food and drink

- It is normal for a person who is dying to gradually feel less like eating or drinking. Some people may still enjoy small amounts of soft food and sips of drinks but can feel too tired at times. We all help the person to take the food and drinks they like for as long as they want to.
- As a person who is dying gets weaker, they need help to take sips of fluid. A drinking beaker or straw can make sipping fluid easier. Moistening the person's lips and tongue with water and using an oral gel helps us keep them comfortable.
- As the process of dying continues the body does not need the same amount of fluid and usually cannot cope with extra fluids given through a drip into a vein. Occasionally we give some extra fluid under the skin, but only if this is still helping to keep the person comfortable. Extra fluids can start to build up in the lungs as the person gets more ill. If this happens, any drip or feeding being given through a tube is stopped because it is no longer helping and may cause breathing difficulties.

2. Changes in breathing

- When someone is dying their need for oxygen lessens and the way they breathe changes. People who have been breathless may feel less breathless at this time.
- As people get more unwell, their breathing may pause for a while, and then start again. They use different muscles to breathe, which means their breathing may look different.
- Sometimes breathing can sound noisy or 'rattling' because the person is no longer able to cough or clear their throat. This can sound distressing to us but is usually not upsetting for the person who is dying because they are less awake. Changing the person's position often helps, or sometimes an injection of medicine may be given.

3. Changes in how the person looks and behaves

- When someone is dying their skin may become pale and moist. Their hands and feet can feel very cold and sometimes look bluish in colour.
- Dying people often feel very tired and will sleep more. Even when they are awake, they may be drowsier than they have been. They will eventually not waken up at all. They may still know that people are with them and be comforted by familiar voices and touch.

4. Changes in nursing and medical care

- We keep a dying person comfortable by making sure their skin, mouth, bladder and bowels are well cared for. A special mattress or bed is sometimes used. Changes in position for comfort and extra pillows to support the person's neck and limbs are often helpful.
- We will check regularly that the person who is dying is comfortable. The people caring for your relative or friend who is dying also want to make sure that you know what is happening and feel well supported. We usually stop doing things like checking blood pressure, temperature or blood sugar levels which are not helpful now.
- The medicines and treatments are reviewed regularly by the doctors and nurses to make sure that we manage any symptoms well and keep the person comfortable. Sometimes medicines are given continuously under the skin using a small battery-operated pump. Extra doses of medicines can be given, if needed, for any symptoms like pain or breathlessness. If the person is dying at home, a supply of these medicines is usually kept in the house 'just in case' they are needed.
- We want to make sure that everyone who is dying has as comfortable and peaceful a death as possible. When people are dying the heart and breathing usually stop gradually. When that happens, giving what is called CPR (cardiopulmonary resuscitation) does not work.
- We talk about what happens when someone dies and why CPR does not work with the person who is dying (if they are able and want to do that) and with the people who are close to them so that everyone knows about what is happening.
- Decisions about resuscitation are shared with everyone who is caring for the person. We put this information in the person's record and tell NHS 24 about it if the person is at home.
- If your relative or friend is dying at home, the staff looking after them will talk with you about what to expect and what to do if you think the person has died.

5. Any questions or worries?

If you are unsure about what is happening or have any questions, please do ask.

Further information

NHS Inform Palliative Care Zone (www.nhsinform.co.uk/PalliativeCare)

Good Life, Good Death, Good Grief (www.goodlifedeathgrief.org.uk/)

Dying Matters (www.dyingmatters.org)

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<http://www.rcgp.org.uk/endoflifecare>
- Supportive and Palliative Care indicators Tool (SPiCT)
www.spict.org.uk
- Scottish Palliative Care Guidelines
www.palliativecareguidelines.scot.nhs.uk
- Amber Care Bundle
<http://www.ambercarebundle.org/homepage.aspx>
- Effective Communication for Healthcare
www.ec4h.org.uk
- Good Life, Good Death, Good Grief
<http://www.goodlifedeathgrief.org.uk>
- Dying Matters
<http://www.dyingmatters.org/>
- NHS Inform - Future Care Planning resources
www.nhsinform.co.uk/PalliativeCare/planningforthefuture
- My Power of Attorney campaign
www.mypowerofattorney.org.uk
- Office of the Public Guardian (Scotland)
www.publicguardian-scotland.gov.uk/power-of-attorney
- Office of the Public Guardian (England and Wales)
<https://www.gov.uk/government/organisations/office-of-the-public-guardian>
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