COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

Person-led Advance Care Planning

& why it matters

Sarah Malik, Clinical Lead and Services Manager, RN

Exercise

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

If you were taken into hospital, what is the one thing that you would like the people taking care of you to know, if you couldn't tell them yourself?

Mission and values

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

- We help people prepare for the end of life. How to talk about it, plan for it, and record their wishes.

- Our vision is a world in which individuals get the end of life care that's right for them.

- We believe everyone should be given the information and support needed to make decisions about their treatment and be helped to plan ahead to ensure that their wishes are known and followed.

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

Free nurse-led Information Line

Publications

Professional training

Research & policy

Community outreach

MyDecisions

Why people call us

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

- Getting older and have strong feelings about the treatment and care they want/don't want
- Have witnessed bad deaths and want to avoid it for themselves
- Want protection from CPR
- Want to understand the different options available – DNACPR, ReSPECT, Advance Decisions, LPA
- Support for dying at home
- Struggling to have their loved one's wishes respected
- Difficulties with clinicians not supporting their treatment preferences
- Upset at finding a DNACPR on their/their loved one's records

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

What we have learned about advance care planning

Need for culture change

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

There is a disconnect between what people want for end-of-life and what they have done to prepare:

- 76% have strong wishes regarding the end of life
- Only 10% want doctors to make the final decision about their treatment

However,

- Only 7% communicate these wishes in advance
- 48% wrongly believe that they have the legal right to make treatment decisions on behalf of their loved ones, if their loved ones lose capacity

Planning ahead

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

Why people do it

- To relieve the responsibility of decision-making from family members
- To be in control of their treatment and care
- To avoid prolonging life when they have no quality of life
- To gain peace of mind in the present

Overall benefits

- Helps clinicians provide person-centred care
- Helps families honour their loved one's wishes
- Reduces unnecessary hospital admissions
- Reduces conflict between clinicians and families

What matters to me

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

"I'm concerned about not being allowed to die when the time comes. I'm frightened of losing control"

"I don't want an injection that would stop me from saying the Shahada"

"I can stop worrying about the future now and just get on and enjoy the here and now… "

"I want to make sure they call my partner and not my family who have not spoken to me in years"

Quality of life and individual choice

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

"I do not want medical treatment to prolong a life that provides no quality, enjoyment or ***independence.****"*

"I enjoy an active lifestyle. If something should happen that left me unable to partake in physical activity, such as walking in the hills, then I could adapt and deal with the fact that that sort of pastime wasn't part of my life anymore. I could also adapt to having support with my personal care, or being incontinent. However, what I could ***not tolerate is not being able to interact meaningfully*** *with my family and friends. By 'meaningfully' I mean being able to make and enjoy a joke, express my opinions, and provide a listening ear to those who need it."*

"I don't want to be in hospital attached to machines and I don't want to be ***kept alive as a vegetable.****"*

Common barriers to planning ahead

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

- No one initiates the conversation
- People don't know what their options are
- They think family or next of kin can make decisions for them
- They think a solicitor is required
- The fear of upsetting people
- Financial and post death focussed

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

Important conversations

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

87% of people want their health and care professionals to know their preferences for treatment and care

77% of people would be willing to explore the topic of DNACPR even if it worried them

Planning ahead cues

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

- “I’m worried about what's going to happen in the future”
- “I know someone who is living in a care home with no quality of life – I don’t want that”
- “I don’t want to be a vegetable”
- “I’m not sure if I need to get anything in place just yet?”
- “Can I have a DNAR?”
- “I’m getting on and I want to start getting things organised”

Find out a bit more…

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

- “Is there anything you don’t want to happen to you?”
- “Is there anywhere you know you would like to live and be cared for?”
- “Who are the important people in your life that you’d like to be involved?”
- “Do you have religious or spiritual beliefs that effect how you want to be cared for?”

Key points to remember

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

- Talking is not enough – treatment and care preferences must be documented and shared if they are to be known and respected
- Respond to cues
- Don’t assume someone else will initiate the conversation

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

Decision-making and the MCA

The Mental Capacity Act (2005)

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

Protects and promotes the right of individuals to make their own decisions. The Act is based on five key principles, which should underpin health and care professionals' approach to decision-making:

1) Presumption of capacity
2) Support to make a decision
3) It's ok to make an unwise decision
4) Best interest
5) Least restrictive option

This act created the LPA for Health and Welfare also gave Advance Decisions to Refuse Treatment statutory force.

End of life treatment – who decides?

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

Having mental capacity means that a person is able to make and communicate a decision for themselves.

If you have the capacity to do so, you have the right to:

- Refuse any medical treatment
- Request treatment (though this is not legally binding)

If you lose capacity and have not made any decisions in advance, your doctor will make a best interest decision

More information - MCA Code of Practice - https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

Planning ahead tools

Person-led tools
Mental Capacity Act 2005

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

Advance Decision to refuse treatment (living will)

- Free to complete
- Legally binding refusal of treatment

Advance Statement

- Opportunity to document your wishes & values

Lasting Power of Attorney for health and welfare

- Costs £82
- No solicitor required
- Covid delays

Advance Decision to Refuse Treatment (living will)

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

- The Mental Capacity Act 2005 s24-26 says:
  - An adult (18+) with the capacity now to make the decision can complete an Advance Decision to Refuse Treatment form
  - Must be clear and specific regarding what is being refused and when
  - If refusing life sustaining treatment must be in writing and witnessed
- Free forms available from Compassion in Dying

What is an Advance Decision?

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

You have the right to refuse any medical treatment such as :

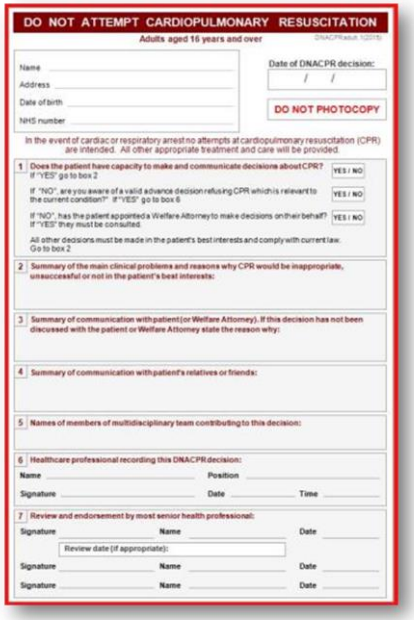
- Cardiopulmonary resuscitation
- Being put on a ventilator if you cannot breathe on your own
- Clinically assisted nutrition and hydration
- Antibiotics for life-threatening infections

What can it not do?

- Ask for your life to be ended
- Refuse the offer of food and drink by mouth
- Nominate someone else to make decisions for you
- Demand treatments
- Refuse basic ‘comfort care’

ADRT & DNACPR

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES



DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION

Adults aged 16 years and over

Name

Address

Date of birth

NHS number

Date of DNACPR decision: / /

DO NOT PHOTOCOPY

In the event of cardiac or respiratory arrest no attempts at cardiopulmonary resuscitation (CPR) are intended. All other appropriate treatment and care will be provided.

1 Does the patient have capacity to make and communicate decisions about CPR? If "YES" go to box 2 — YES / NO

If "NO", are you aware of a valid advance decision refusing CPR which is relevant to the current condition? If "YES" go to box 6 — YES / NO

If "NO", has the patient appointed a Welfare Attorney to make decisions on their behalf? If "YES" they must be consulted. — YES / NO

All other decisions must be made in the patient's best interests and comply with current law. Go to box 2

2 Summary of the main clinical problems and reasons why CPR would be inappropriate, unsuccessful or not in the patient's best interests:

3 Summary of communication with patient (or Welfare Attorney). If this decision has not been discussed with the patient or Welfare Attorney state the reason why:

4 Summary of communication with patient's relatives or friends:

5 Names of members of multidisciplinary team contributing to this decision:

6 Healthcare professional recording this DNACPR decision:
Name Position
Signature Date Time

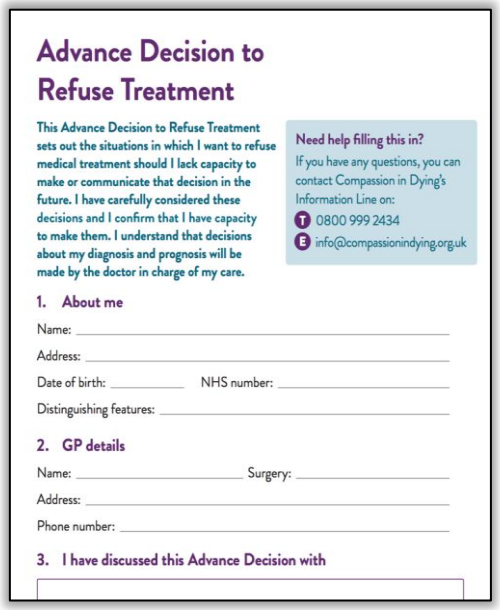
7 Review and endorsement by most senior health professional:
Signature Name Date
Review date (if appropriate):
Signature Name Date
Signature Name Date

DNACPR

- Clinician led
- Only resuscitation
- Communication tool

ADRT

- Person led
- Refuse any treatment
- Legally binding



Advance Decision to Refuse Treatment

This Advance Decision to Refuse Treatment sets out the situations in which I want to refuse medical treatment should I lack capacity to make or communicate that decision in the future. I have carefully considered these decisions and I confirm that I have capacity to make them. I understand that decisions about my diagnosis and prognosis will be made by the doctor in charge of my care.

Need help filling this in?
If you have any questions, you can contact Compassion in Dying's Information Line on:
T 0800 999 2434
E info@compassionindying.org.uk

1. About me

Name: _____

Address: _____

Date of birth: _____ NHS number: _____

Distinguishing features: _____

2. GP details

Name: _____ Surgery: _____

Address: _____

Phone number: _____

3. I have discussed this Advance Decision with

@AGoodDeath

Advance Statement

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

- It is an expression of your wishes
- An opportunity to document what's important to you
- Can say what you do want and can be helpful for the best interest decision making process
- Not legally binding

Lasting Power of Attorney for health & welfare

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

Lasting Power of Attorney for health and welfare

- Costs £82
- No solicitor required
- Processing delays
- LPA helpline – 0300 456 0300

How they work together

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

- Written evidence of a person's wishes is always helpful
- An attorney can make any decision about health and care, not just for refusing treatment.
- But they are bound by the MCA and best interests decisions, so an ADRT and Advance Statement are important evidence of someone's wishes.
- You can refer to an ADRT in the preferences or instructions sections of the LPA form – language is important here.

Planning Ahead – Summary of tools

	What is it for?	How do I know if it is legally binding?	What are my responsibilities as a healthcare professional?
ADRT	Refusing treatment	Valid & applicable	• Discuss and include in medical records • Make efforts to find it • If valid & applicable must follow
Advance Statement	Expressing wishes, values & beliefs in relation to treatment or care	Not legally binding	• Must take into account when making a best interests decision
LPA	Giving another person authority to make decisions about treatment and care	Stamped on all pages by the OPG	To check: • Jointly or severally • Life-sustaining treatment • Preferences & instructions To facilitate consultations
DNACPR	Refusing CPR	Communication tool	• Check medical records

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

Points to remember

Improving understanding of advance care planning

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

- Any adult can plan ahead – you don't need to be old or ill but you do need to have the capacity to make this decision now
- Health and care professionals can help with the decision-making process but do not need to agree with the decision
- Next of kin do not have the legal right to make decisions – but they should be involved in the decision-making process
- Getting affairs in order should not just be post-death focused
- Solicitors are not needed to complete Advance Decisions

In the absence of advance care planning

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

"Dad was 81 and was taken into hospital with sepsis due to a failed knee replacement. He was on a morphine driver and in and out of consciousness. The doctor came in and said he was going to remove his leg but Dad had previously refused an amputation and so I knew he wouldn't want this. I told them and said I didn't give permission but was told I had no say in it and they wheeled him to theatre. I feel as though all our wishes were ignored. I wasn't prepared for the lack of control I had over decisions, I wish he'd have made a Living Will or a Lasting Power of Attorney, because the things he said to me verbally that he wanted were not adhered to."

"My mother's death was not as she wished. She had not made any arrangements before her dementia stopped her being able to do so. She had discussed death with me 40 years before. I was unable to help my mother in the way she had told me and I regret that."

Good practices lead to better experiences

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

My 91 year old husband was in hospital suffering from Covid…the registrar was very helpful, we discussed resuscitation fully and agreed to let my husband die peacefully. I was impressed by the time and consideration shown to me."

"Because the Advance Decision was in place and I had talked to my husband about it, it really did put me in a position where I knew what to do and I was able to help him die at home as was his wish"

What matters to people

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

" I have a ReSPECT form, and an Advance Decision. I may live until I'm 40, and I may live until I'm 80…What is important to me is that I die peacefully. My paperwork is not a wish to die but a wish to not suffer. I feel comforted knowing that there won't be a discussion at a highly stressful time, were anything to happen to me"

(Rebecca, diagnosed with stage 3 bowel cancer)

"I believe that my husband's death, although far from easy, was easier than it would have been because of his Advance Decision. He had more control, and was able to stay at home, with his friends and family around him because of this."

(Husband died of MND)

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

“I can stop worrying about the future now and just get on and enjoy the here and now… ”

Get in touch

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

If you'd like to know more about anything we've discussed then please email me

sarah.malik@compassionindying.org.uk

Or signpost people to our service

info@compassionindying.org.uk

Info line 0800 999 2434 11am -3pm

www.compassionindying.org.uk