End of Life Care Documentation

26th January 2023

The webinar will begin shortly

hcpa

Hertfordshire

Contents

- Welcome
- Importance of ACP
- Importance of clear documentation
- DNACPR guidance
- Documentation best practice
- ReSPECT – when and where?
- Q&As

Importance of ACP

Dr Mark Andrews

Clinical lead – Palliative and End of Life Care

HWE ICB

Hertfordshire County Council DNACPR Guidance

Hilary Gardener

Strategic Liasion Nurse

DNACPR

A Step-by-Step Guide to Putting a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Order in Place

S.Evis@nhs.net – Named Nurse Adult Safeguarding ICB

Hilary.gardener@hertfordshire.gov.uk – Strategic Liaison Nurse for Hertfordshire Primary Health

Rationale

Raised By Keith Dodd as Safeguarding Lead for HCC

Need for greater understanding :-

1. **For Care Providers and Family Carers on What their role is with the Best Interest Element of a DNACPR where someone does not have the capacity to take part in the DNACPR discussion themselves.**
2. **For people who have capacity to be involved to as great a degree as possible in the decision process.**
3. **For Health professionals to be aware of the importance and legal requirement to involve others in THIS decision.**
4. **For Social Care practitioners to have a greater understanding of what they SHOULD see documented in a DNACPR document and know what and how to challenge**

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Background to Tool Development

- Steph and Hilary worked together to review other approaches and the legalities and create the tool –
- We Sought permission from Turning Point and Learning Disability England to adapt their DNACPR support pack.
- This was a comprehensive tool but aimed solely at carers and had a negatively challenging tone and we wanted to create a tool that enabled a joint approach between health and social care
- We created a first draft and then adapted based on feedback from PohWer, GP clinicians, Strategic Liaison Nurse, End of Life clinicians

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Content of The Guide

A Step-by-Step Guide to Putting a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Order in Place

The Guide is a 5 Page Document

Page 1- This Explains what CPR is and why it is sometimes Clinically NOT in a persons Best Interest.

Page 2 – This explains WHEN and WHY a DNACPR can be put in place

Page 3 – This explains the CORE principles of the Mental Capacity Act and How this applies to DNACPR

Page 4 – This is the Flow Chart to Help Carers, Clinicians and the person themselves understand what should happen and when and know how to question this.

Page 5 – Links and contacts

The Flow Chart

Flow chart

A Person becomes unwell and the Doctor decides that , should the person go into cardiac arrest the likelihood of them surviving and staying alive is unlikely. The Doctor makes the medical decision to put a DNA CPR in place.

Discussion

By Law, the Doctor MUST discuss with the patient and explain WHY they feel this is medically in the persons best interest and record this conversation on the form.

DNA CPRs DO NOT stop ALL treatment – It JUST means that if the persons heart stops it would be unsuccessful to try and re start it and not in the persons best interest

Does the person have the mental capacity to understand this conversation ?

NO

YES

Flow Chart Part 2 THE YES ROUTE

The Doctor should –

Use the DNA CPR easy read to support them to understand

Consult people who know them well to establish if they feel they can help them understand

In conjunction with people who know them well is it felt that they cannot understand and it will cause undue distress to pursue this?

They do not understand

They do understand

The conversation is recorded on the form. If the person is questioning the Doctor's decision about WHY CPR would not be successful THEN they can request a second opinion. They Cannot make this clinical decision BUT they have every right to question to ensure it is a sound decision based on medical evidence and NOT value based.

The people who know them well should support in asking these questions - see next box

Flow Chart Part 3

The YES Route

The Doctor should –

Hold the DNA CPR conversation with the Next of Kin AND people who know the person well in their day to day lives [This may not be the NOK]

Detail the reasons they believe CPR would not be a medically sound decision, the impact it could have and why they do not believe it is in the persons best interest.

The NOK and people who know them well should question and ensure that this is based on medical grounds with no value base according to age or learning disability. e.g. ASK: "if someone the same age without a learning disability was in exactly the same situation would you consider it not in their best interest to resuscitate?" or "If someone 20 years younger was presenting with the exact same health condition would consider it in their best interest not to resuscitate"

Remember – Doctors should review and remove a DNA CPR when the person is discharged from Hospital if it related to the health episode they were admitted for

People who support the person should check and question this before discharge

Flow Chart Part 2 The NO Route

The Doctor should –

Use the DNA CPR easy read to support them to understand

Consult people who know them well to establish if they feel they can help them understand

In conjunction with people who know them well is it felt that they cannot understand and it will cause undue distress to pursue this?

They do not understand

They do understand

The conversation is recorded on the form. If the person is questioning the Doctor's decision about WHY CPR would not be successful THEN they can request a second opinion. They Cannot make this clinical decision BUT they have every right to question to ensure it is a sound decision based on medical evidence and NOT value based.

The people who know them well should support in asking these questions - see next box

Flow Chart Part 3 The NO Route

The Doctor should –

Hold the DNA CPR conversation with the Next of Kin AND people who know the person well in their day to day lives [This may not be the NOK]

Detail the reasons they believe CPR would not be a medically sound decision, the impact it could have and why they do not believe it is in the persons best interest.

The NOK and people who know them well should question and ensure that this is based on medical grounds with no value base according to age or learning disability. e.g. ASK: "if someone the same age without a learning disability was in exactly the same situation would you consider it not in their best interest to resuscitate?" or "If someone 20 years younger was presenting with the exact same health condition would consider it in their best interest not to resuscitate"

Remember – Doctors should review and remove a DNA CPR when the person is discharged from Hospital if it related to the health episode they were admitted for

People who support the person should check and question this before discharge

Round Up

The Tool Aims to Aid Understanding that

- DNACPR is only ONE aspect of advance planning
- It is a Clinical Decision
- People need to feel empowered to participate in the decision discussion by questioning whether it is a clinical decision and check it has no Value base to it.
- Clinicians need to see the discussion as a route to ensuring they are making a sound clinical decision with no unconscious bias.
- Social Care practitioners can check the DNACPR process has been fully followed and understand what and how they can question this.

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Any Questions ????

Here is a Link to the Guide

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Care Home Documentation Best Practice – Advance Care Plans

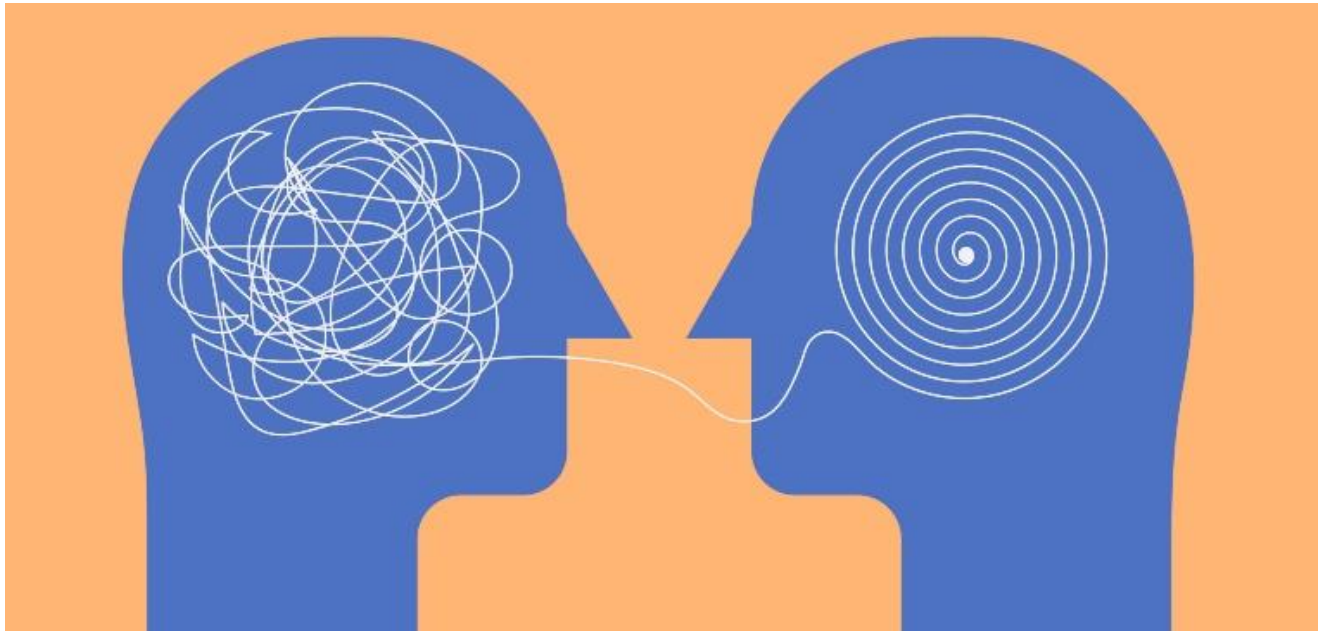
Jessica Ives-Keeler

Clinical Education Manager

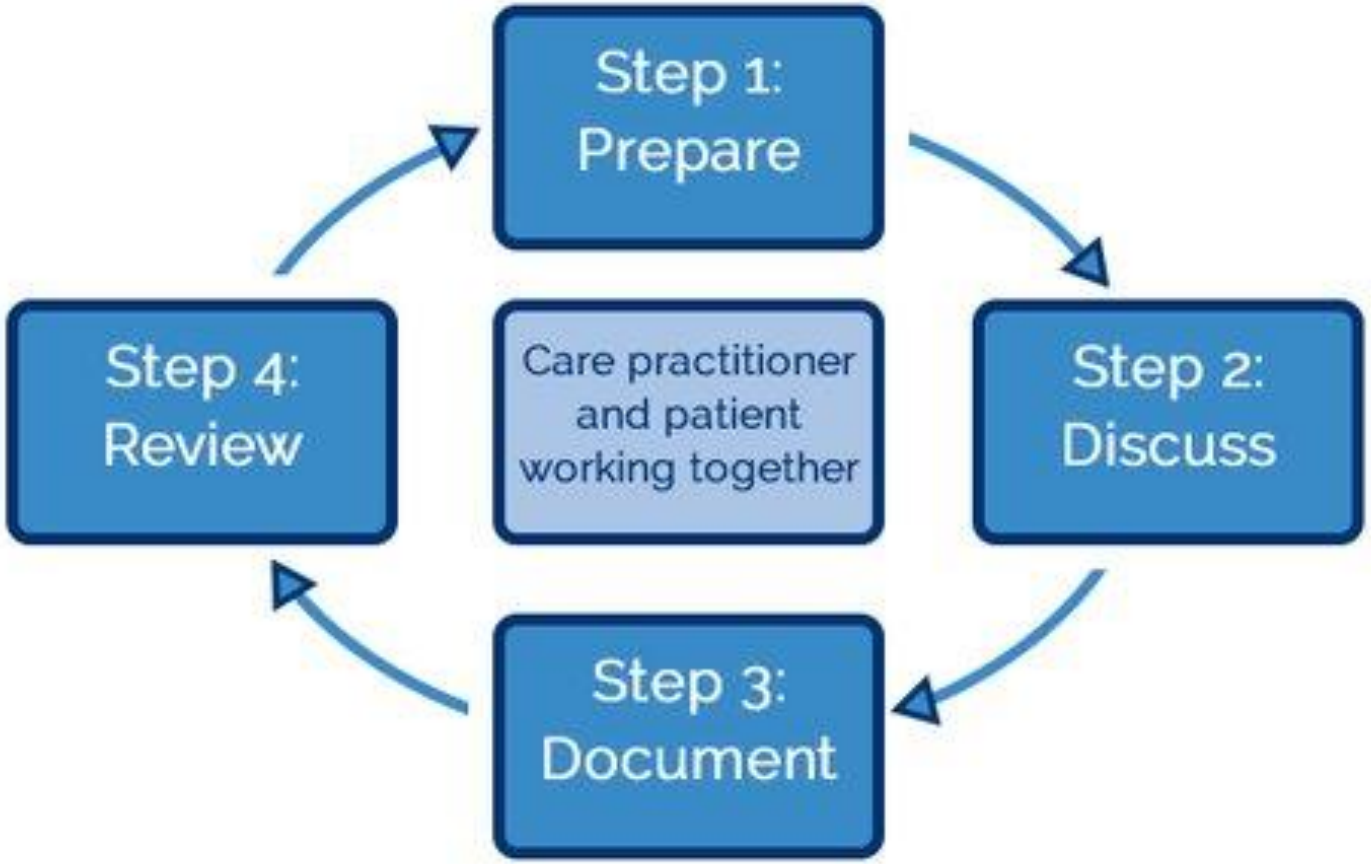
HCPA

Mental Capacity and Decision Making

- When the person has capacity, ACPs should be discussed with them
- When the person lacks capacity, ACPs should be discussed with family members
  - Mental Capacity assessment must be completed
- Both of the above scenarios need to be clearly documented



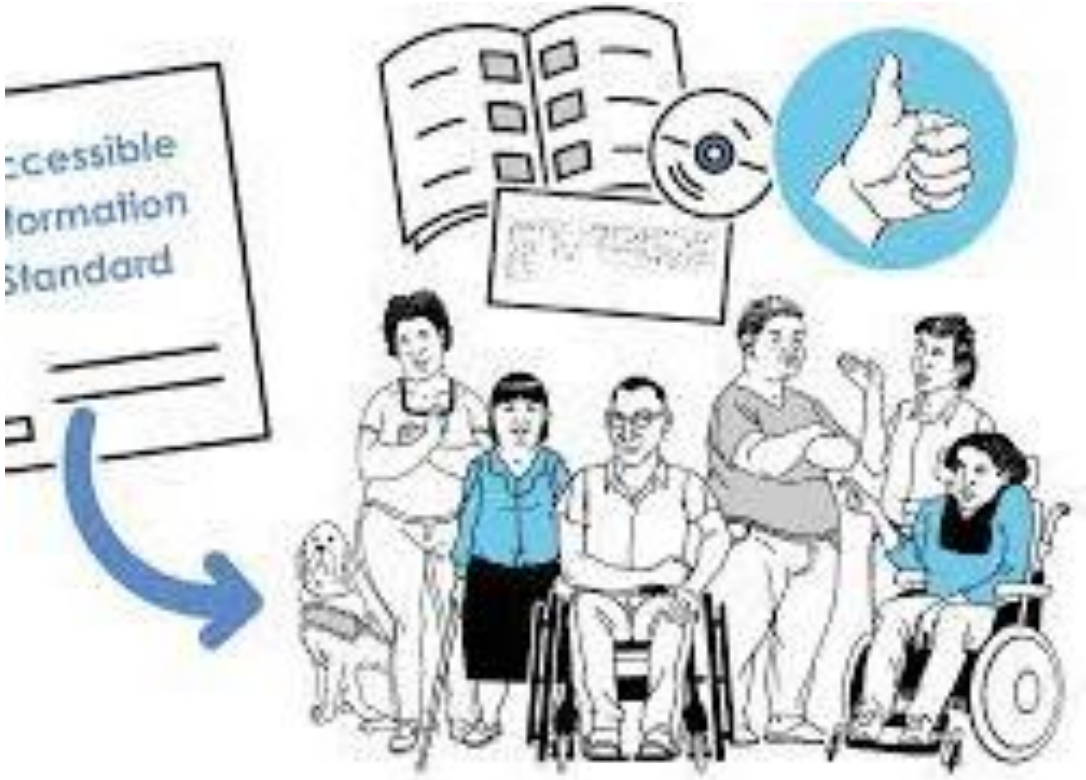
Reviewing the plan



"Both Mrs G and her partner had to cope with her symptoms and pain alone because there was no review of her needs." Dying without dignity report

Providing the information in an accessible way

- Accessible information standard – now being inspected against in CQC key questions
- Tips for communicating with people with a learning disability



Personalised care plans

- CQC:
  - “It is unacceptable for advance care plans, with or without DNAR form completion to be applied to groups of people of any description. These decisions must continue to be made on an individual basis according to need.”

Personal history	Social circumstances	Previous wishes	Religion, cultural factors	Goals, aspirations

Sharing the care plan

- Always gain consent prior to sharing information and record this
- Ensure care plans are transferred if the person changes care provider
- Share the care plan with any appropriate involved healthcare professionals

Examples

Dementia UK

Compassion in Dying – Advanced Decision

Macintyre – easy read plan

ReSPECT – what, when and where?

Nicky Wood

Learning Development and Education Lead

Isabel Hospice

Isabel Hospice

Together we care

ReSPECT

Recommended Summary Plan for Emergency Care and Treatment

Level 2 Training

East and North Hertfordshire

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RESPECT

Recommended Summary Plan for Emergency Care and Treatment

Isabel Hospice
Together we care

- Recommended
- Summary
- Plan for
- Emergency
- Care and
- Treatment

An alternative process…

…for discussing, making and recording recommendations about future emergency care and treatment, including CPR

Records treatments to be considered…

…as well as those that are not wanted or would not work

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ReSPECT – who is it for?

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Together we care

The process can be for everyone but is especially relevant to those:

- With particular health needs that may involve a sudden deterioration in health
- With a life limiting condition, such as advanced organ failure, advanced cancer or frailty
- At risk of sudden events, such as epilepsy or diabetic crisis.
- Who have strong feelings about treatment or outcomes

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ReSPECT - how to read

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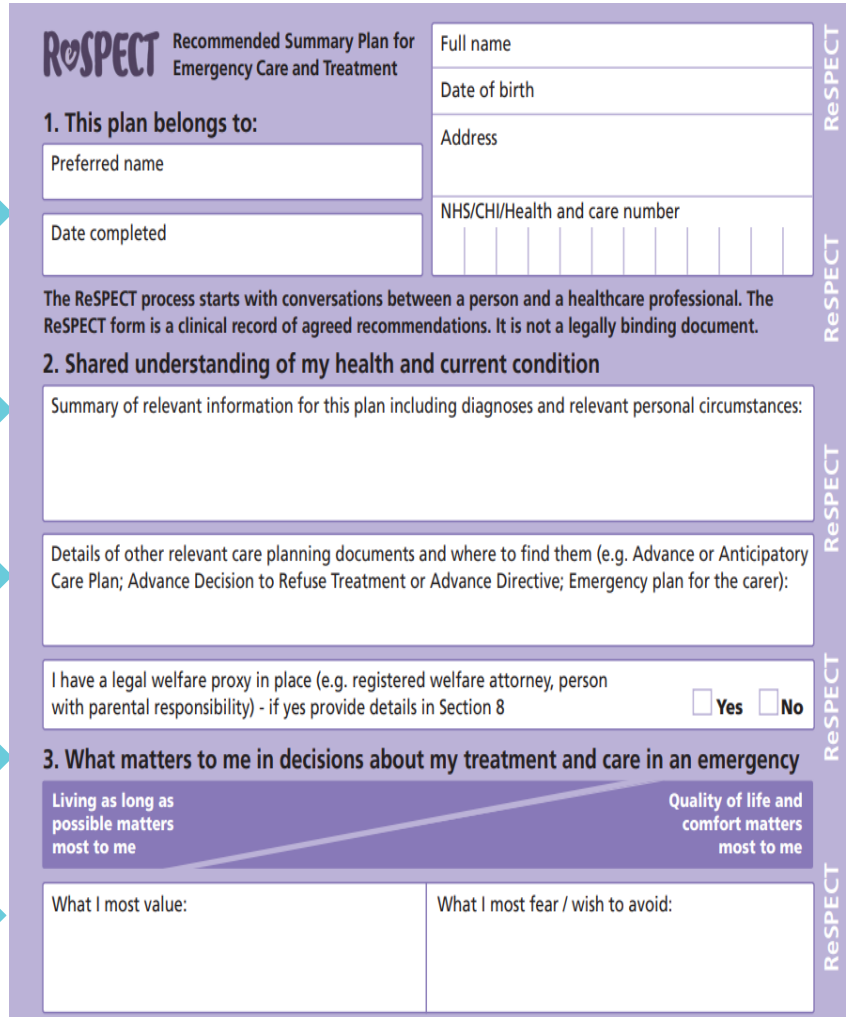
- Records the person's details and the date of completion (addressograph can be used)
- Summarises relevant details about their condition
- Records details of other relevant planning documents e.g. ADRT
- this scale may have been used to help them to identify priorities for their care
- this box may record what is important to them (optional)



ReSPECT Recommended Summary Plan for Emergency Care and Treatment

Full name

Date of birth

Address

NHS/CHI/Health and care number

1. This plan belongs to:

Preferred name

Date completed

The ReSPECT process starts with conversations between a person and a healthcare professional. The ReSPECT form is a clinical record of agreed recommendations. It is not a legally binding document.

2. Shared understanding of my health and current condition

Summary of relevant information for this plan including diagnoses and relevant personal circumstances:

Details of other relevant care planning documents and where to find them (e.g. Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency plan for the carer):

I have a legal welfare proxy in place (e.g. registered welfare attorney, person with parental responsibility) - if yes provide details in Section 8 ☐ Yes ☐ No

3. What matters to me in decisions about my treatment and care in an emergency

Living as long as possible matters most to me

Quality of life and comfort matters most to me

What I most value:

What I most fear / wish to avoid:

ReSPECT

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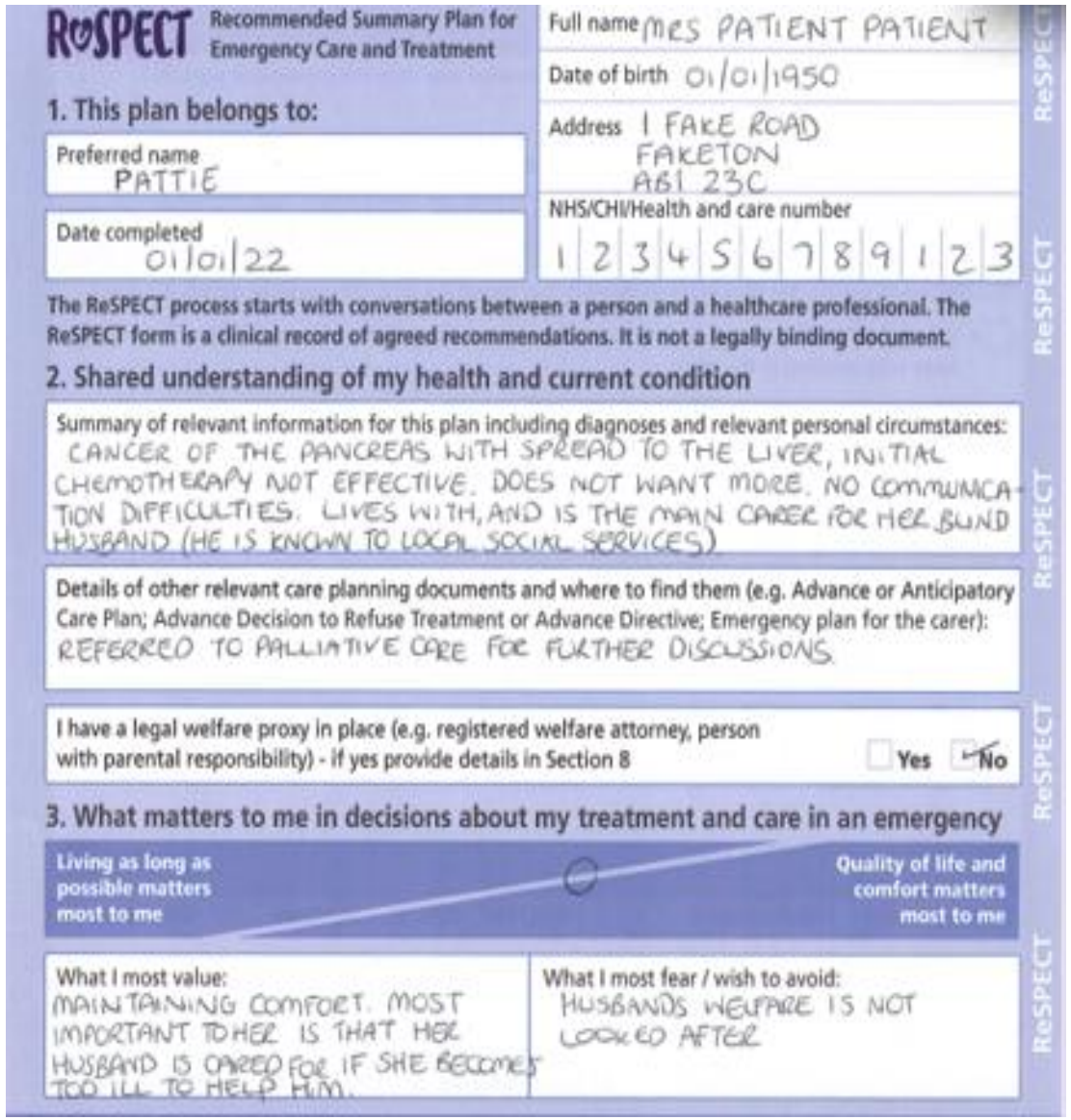

ReSPECT Recommended Summary Plan for Emergency Care and Treatment

Full name MRS PATIENT PATIENT

Date of birth 01/01/1950

Address 1 FAKE ROAD
FAKETON
AB1 23C

NHS/CHI/Health and care number 1 2 3 4 5 6 7 8 9 1 2 3

1. This plan belongs to:

Preferred name PATTIE

Date completed 01/01/22

The ReSPECT process starts with conversations between a person and a healthcare professional. The ReSPECT form is a clinical record of agreed recommendations. It is not a legally binding document.

2. Shared understanding of my health and current condition

Summary of relevant information for this plan including diagnoses and relevant personal circumstances:
CANCER OF THE PANCREAS WITH SPREAD TO THE LIVER, INITIAL CHEMOTHERAPY NOT EFFECTIVE. DOES NOT WANT MORE. NO COMMUNICATION DIFFICULTIES. LIVES WITH, AND IS THE MAIN CARER FOR HER BLIND HUSBAND (HE IS KNOWN TO LOCAL SOCIAL SERVICES)

Details of other relevant care planning documents and where to find them (e.g. Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency plan for the carer):
REFERRED TO PALLIATIVE CARE FOR FURTHER DISCUSSIONS

I have a legal welfare proxy in place (e.g. registered welfare attorney, person with parental responsibility) - if yes provide details in Section 8 ☐ Yes ☑ No

3. What matters to me in decisions about my treatment and care in an emergency

Living as long as possible matters most to me — Quality of life and comfort matters most to me

What I most value:
MAINTAINING COMFORT. MOST IMPORTANT TO HER IS THAT HER HUSBAND IS CARED FOR IF SHE BECOMES TOO ILL TO HELP HIM.

What I most fear / wish to avoid:
HUSBANDS WELFARE IS NOT LOOKED AFTER

ReSPECT

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ReSPECT - how to interpret

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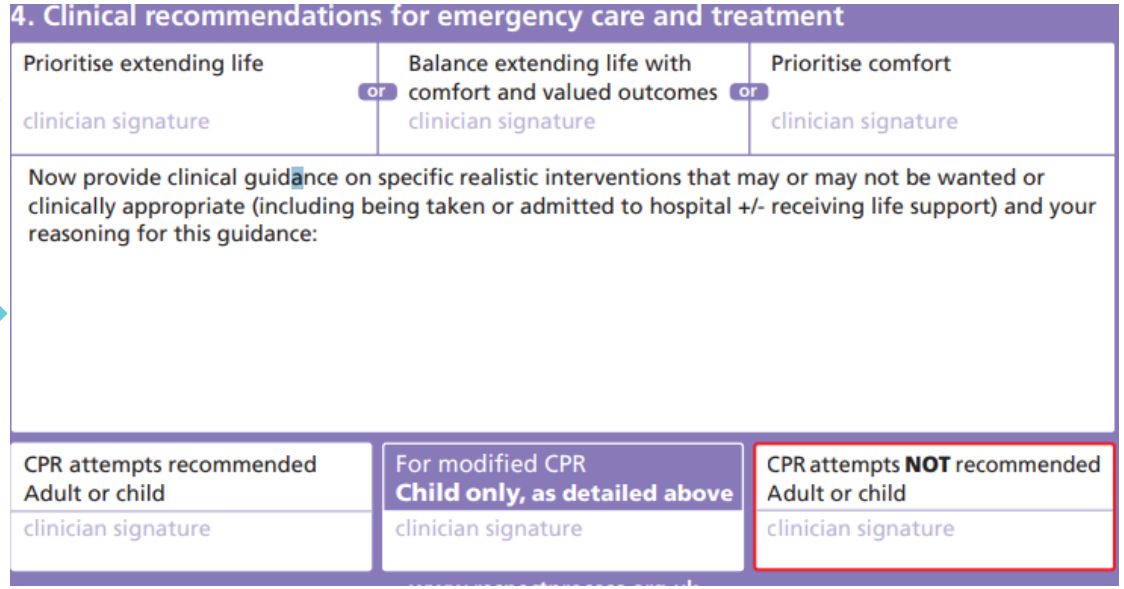
Section 4 records agreed recommendations to guide decision-making (still front page):

- The main aim of treatment
- specific types of care and treatment that the person would or would not want that would not work in their situation
- whether or not attempted CPR is recommended



4. Clinical recommendations for emergency care and treatment

Prioritise extending life	or	Balance extending life with comfort and valued outcomes	or	Prioritise comfort
clinician signature		clinician signature		clinician signature

Now provide clinical guidance on specific realistic interventions that may or may not be wanted or clinically appropriate (including being taken or admitted to hospital +/- receiving life support) and your reasoning for this guidance:

CPR attempts recommended Adult or child	For modified CPR **Child only, as detailed above**	CPR attempts **NOT** recommended Adult or child
clinician signature	clinician signature	clinician signature

These recommendations are there to guide you when making immediate decisions in an emergency

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ReSPECT Emergency Guidance

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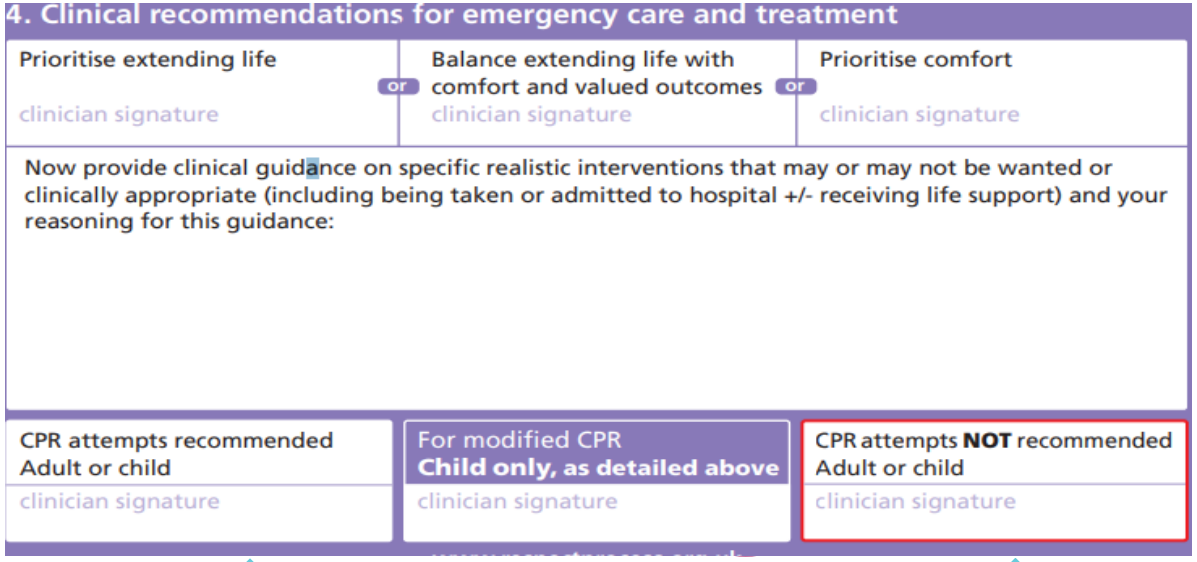
- A ReSPECT form does not always mean DNACPR.
- You must get in the habit of looking into both boxes on the form to see which applies.



FOR CPR

NOT FOR CPR

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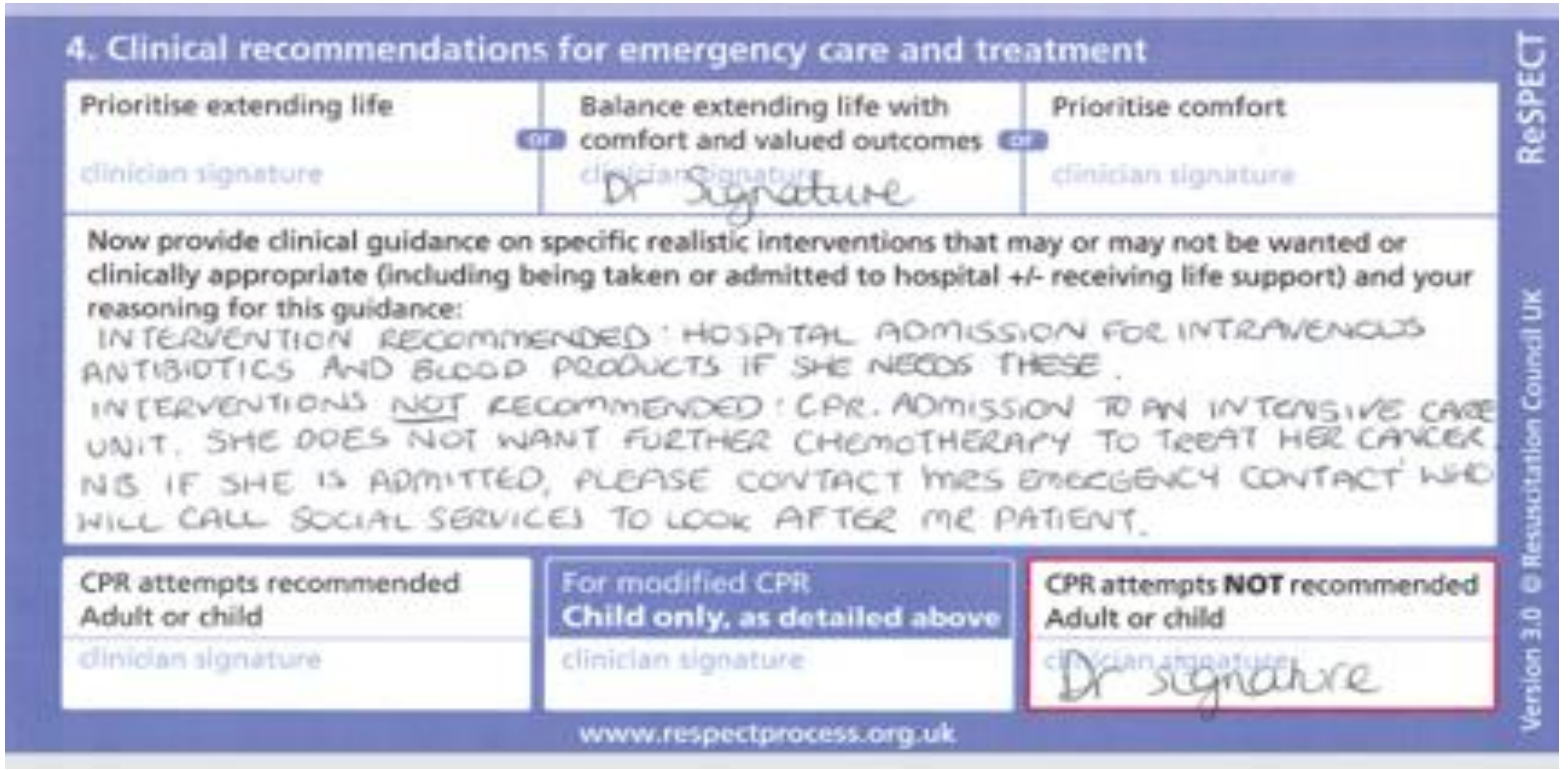

4. Clinical recommendations for emergency care and treatment

Prioritise extending life	Balance extending life with comfort and valued outcomes	Prioritise comfort
clinician signature	Dr Signature	clinician signature

Now provide clinical guidance on specific realistic interventions that may or may not be wanted or clinically appropriate (including being taken or admitted to hospital +/- receiving life support) and your reasoning for this guidance:

INTERVENTION RECOMMENDED: HOSPITAL ADMISSION FOR INTRAVENOUS ANTIBIOTICS AND BLOOD PRODUCTS IF SHE NEEDS THESE.

INTERVENTIONS NOT RECOMMENDED: CPR. ADMISSION TO AN INTENSIVE CARE UNIT. SHE DOES NOT WANT FURTHER CHEMOTHERAPY TO TREAT HER CANCER.

NB IF SHE IS ADMITTED, PLEASE CONTACT MRS EMERGENCY CONTACT WHO WILL CALL SOCIAL SERVICES TO LOOK AFTER ME PATIENT.

CPR attempts recommended Adult or child	For modified CPR **Child only, as detailed above**	CPR attempts **NOT** recommended Adult or child
clinician signature	clinician signature	Dr signature

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ReSPECT - how to interpret

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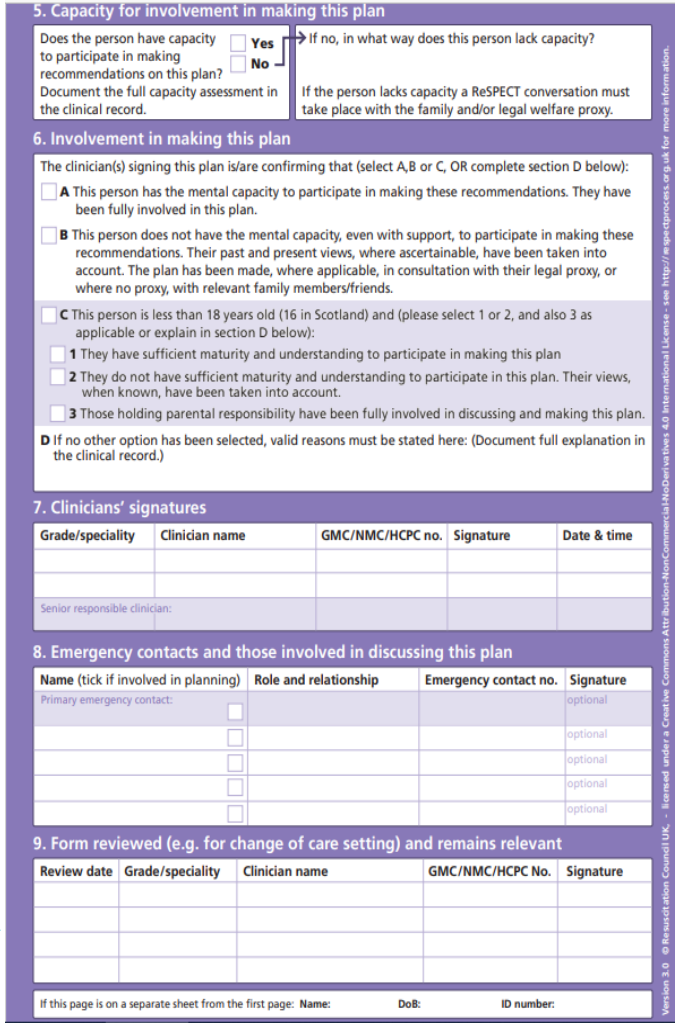
Sections 5-8 should be completed fully

If the patient lacks capacity a mental capacity assessment needs to be completed and recorded in the medical notes

- Section 7 should be signed by clinicians to confirm that all statements and recommendations are valid
- Section 8 lists emergency contacts
- Section 9 may be blank for use by a clinician reviewing this ReSPECT form at a future time or may record a review confirming validity



5. Capacity for involvement in making this plan

Does the person have capacity to participate in making recommendations on this plan? Document the full capacity assessment in the clinical record. ☐ Yes ☐ No → If no, in what way does this person lack capacity?

If the person lacks capacity a ReSPECT conversation must take place with the family and/or legal welfare proxy.

6. Involvement in making this plan

The clinician(s) signing this plan is/are confirming that (select A,B or C, OR complete section D below):

☐ **A** This person has the mental capacity to participate in making these recommendations. They have been fully involved in this plan.

☐ **B** This person does not have the mental capacity, even with support, to participate in making these recommendations. Their past and present views, where ascertainable, have been taken into account. The plan has been made, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends.

☐ **C** This person is less than 18 years old (16 in Scotland) and (please select 1 or 2, and also 3 as applicable or explain in section D below):

☐ **1** They have sufficient maturity and understanding to participate in making this plan

☐ **2** They do not have sufficient maturity and understanding to participate in this plan. Their views, when known, have been taken into account.

☐ **3** Those holding parental responsibility have been fully involved in discussing and making this plan.

D If no other option has been selected, valid reasons must be stated here: (Document full explanation in the clinical record.)

7. Clinicians' signatures

Grade/speciality	Clinician name	GMC/NMC/HCPC no.	Signature	Date & time
Senior responsible clinician:				

8. Emergency contacts and those involved in discussing this plan

Name (tick if involved in planning)	Role and relationship	Emergency contact no.	Signature
Primary emergency contact: ☐			optional
☐			optional
☐			optional
☐			optional
☐			optional

9. Form reviewed (e.g. for change of care setting) and remains relevant

Review date	Grade/speciality	Clinician name	GMC/NMC/HCPC No.	Signature

If this page is on a separate sheet from the first page: Name: DoB: ID number:

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ReSPECT who completes it?

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- Should be completed by a GP/doctor/competent nurse looking after the patient
- This clinician should have completed Advanced Communications skills + DNACPR training in order to be the person to sign the form.

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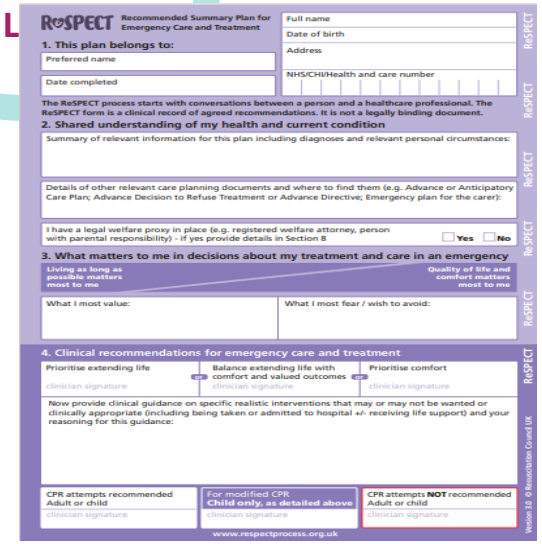
ReSPECT — who keeps it?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1. This plan belongs to:
Preferred name
Date completed
Full name
Date of birth
Address
NHS/CHI/Health and care number

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2. Shared understanding of my health and current condition
Summary of relevant information for this plan including diagnoses and relevant personal circumstances:
Details of other relevant care planning documents and where to find them (e.g. Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency plan for the carer):
I have a legal welfare proxy in place (e.g. registered welfare attorney, person with parental responsibility) - if yes provide details in Section 8 ☐ Yes ☐ No

3. What matters to me in decisions about my treatment and care in an emergency
Living as long as possible matters most to me
Quality of life and comfort matters most to me
What I most value:
What I most fear / wish to avoid:

4. Clinical recommendations for emergency care and treatment
Prioritise extending life — clinician signature
Balance extending life with comfort and valued outcomes — clinician signature
Prioritise comfort — clinician signature
Now provide clinical guidance on specific realistic interventions that may or may not be wanted or clinically appropriate (including being taken or admitted to hospital +/- receiving life support) and your reasoning for this guidance:
CPR attempts recommended Adult or child — clinician signature
For modified CPR: Child only, as detailed above — clinician signature
CPR attempts NOT recommended Adult or child — clinician signature

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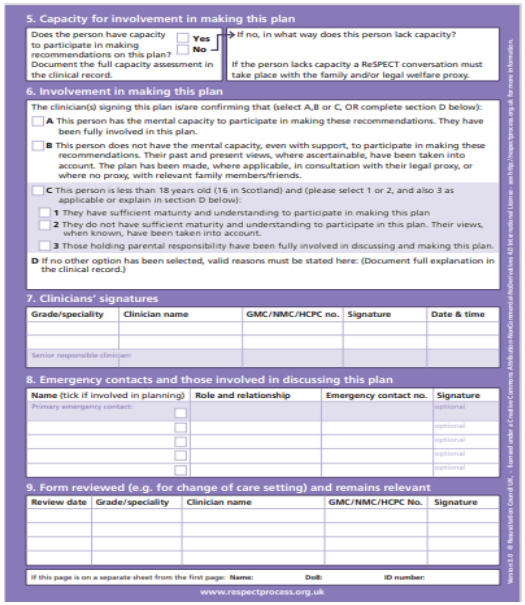
5. Capacity for involvement in making this plan
Does the person have capacity to participate in making recommendations on this plan? Document the full capacity assessment in the clinical record. ☐ Yes ☐ No
If no, in what way does this person lack capacity?
If the person lacks capacity a ReSPECT conversation must take place with the family and/or legal welfare proxy.

6. Involvement in making this plan
The clinician(s) signing this plan is/are confirming that (select A,B or C, OR complete section D below):
A This person has the mental capacity to participate in making these recommendations. They have been fully involved in this plan.
B This person does not have the mental capacity, even with support, to participate in making these recommendations. Their past and present views, where ascertainable, have been taken into account. The plan has been made, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends.
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2 They do not have sufficient maturity and understanding to participate in this plan. Their views, when known, have been taken into account.
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7. Clinicians' signatures
Grade/speciality | Clinician name | GMC/NMC/HCPC no. | Signature | Date & time
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Name (tick if involved in planning) | Role and relationship | Emergency contact no. | Signature
Primary emergency contact:

9. Form reviewed (e.g. for change of care setting) and remains relevant
Review date | Grade/speciality | Clinician name | GMC/NMC/HCPC No. | Signature

If this page is on a separate sheet from the first page: Name: DoB: ID number:

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- Recommendations on the form are discussed and shared to ensure future decisions about the person's care are in their best interests
- Paper versions of the form should be kept by or with the person and should be accessible immediately to any clinician needing to make an immediate decision in a crisis
- Electronic versions must be similarly accessible
- Local systems must ensure that all versions are included in any cancellation or change to a **ReSPECT** form

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ReSPECT frequently asked Qs

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Together we care

- **Is it legally binding?**
  - is not a legally binding document, but you should have good reason for ignoring its recommendations
- **Does it replace advance care plans?**
  - **ReSPECT** can complement other documents such as advance care plans but does not replace them
- **Will existing DNACPR forms still be valid?**
  - Existing DNACPR forms will still be valid and will not be replaced unless there is a change in condition.
- **If the patient has two forms which one is valid?**
  - The most recent form, whether DNACPR or ReSPECT will be valid. Older forms should be crossed through with CANCELLED written on them before filing in patient records.

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RESPECT frequently asked Qs

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- **Can it be photocopied?**
  - should not be photocopied for clinical use – if presented with a photocopy consider quickly and carefully why, and whether the recommendations are current and valid
- **Which areas use the document?**
  - Nationally, many areas have already introduced it and many others are in the process of implementing.

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ReSPECT What happens on discharge?

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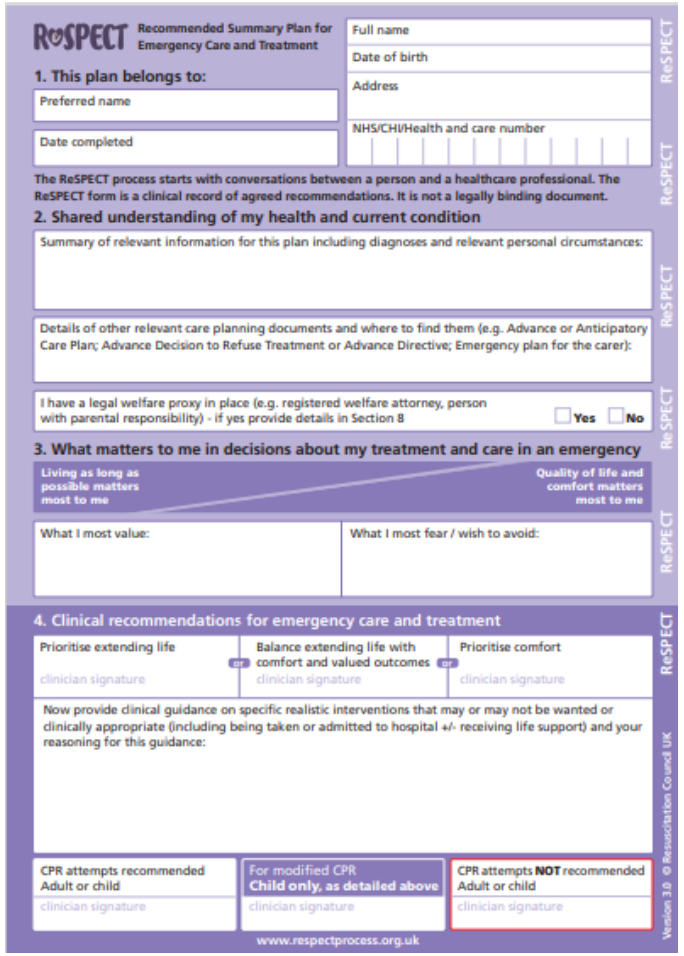
- Document goes with patient and stays with patient
- Documentation on the discharge letter needs to mention a ReSPECT form has been started



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NHS/CHI/Health and care number

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I have a legal welfare proxy in place (e.g. registered welfare attorney, person with parental responsibility) - if yes provide details in Section 8 ☐ Yes ☐ No

3. What matters to me in decisions about my treatment and care in an emergency

Living as long as possible matters most to me — Quality of life and comfort matters most to me

What I most value:

What I most fear / wish to avoid:

4. Clinical recommendations for emergency care and treatment

Prioritise extending life — clinician signature
OR
Balance extending life with comfort and valued outcomes — clinician signature
OR
Prioritise comfort — clinician signature

Now provide clinical guidance on specific realistic interventions that may or may not be wanted or clinically appropriate (including being taken or admitted to hospital +/- receiving life support) and your reasoning for this guidance:

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For modified CPR **Child only, as detailed above** — clinician signature

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ReSPECT - Further Information

Isabel Hospice
Together we care

Further training available via:

https://www.respectprocess.org.uk/learning

Any questions?

Thank you for joining us

Please remember to leave feedback

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