

What matters - the process of thinking ahead

Serious illness and ageing bring challenges that many of us prefer to avoid thinking about. At the same time many of us fear loss of control about decisions relating to our health care.

Thinking ahead and writing down what matters to you can be a daunting process. However if no one else knows what is important to you, your preferences and choices may not be taken into consideration. It may be difficult to talk to your family and they may not agree with you, but having these conversations can help inform decisions that sometimes need to be made at a time of a crisis. Writing your preferences down will ensure your wishes are respected as far as possible.

This booklet is designed to help you start making informed choices. You may not feel that you know enough about what is available to you or what choices you have about your care. It will direct you towards the people who may be able to help you. This booklet belongs to you – it is for you and about you. You can show it to anyone who is involved in your care. It is important to remember that you can add to this booklet as often as you like and change your decisions at any time in the light of altered circumstances.

The following pages highlight some important questions that you may or may not have already given some thought to. Your answers to these questions will help to shape your care in the future. It is an opportunity to reflect on what you do and don't want in realistic terms. You can also record details of those involved in your care for handy reference.

Writing in this booklet creates an 'advance statement' (see page 9), not a legal document. It is intended to help you think about your future ahead of time and influence a thorough and individualized approach to your care. It could also be used as guidance about your wishes and decisions should you ever lack capacity to voice them yourself.

Your personal preferences and choices

1. Who knows you well and understands what is important to you?

Please add their full contact details to page 10

2. Who do you view as your next of kin?

Please add their full contact details to page 10

3. Who or what supports you when things are difficult?

4. Do you have a particular faith or belief system that is important to you? Please give details:

Would you like to talk to anyone about it?

Yes

No

If Yes, who?

5. What concerns you most about your health, now and for the future?

6. Are there discussions with family and/or friends you feel would be helpful?

Would you like anyone to help you with this?
If Yes, who?

Yes

No

7. Where would you like to be cared for if you are no longer able to care for yourself?

First preference

Second preference

8. Bearing in mind that your circumstances may change, where would you prefer to be cared for when you are dying? e.g. home, care home, hospital, or hospice.

First preference

Second preference

9. Have you made a will?
If Yes, where is it held?

Yes

No

If no, would you like to discuss how to make a will?

Yes

No

10. **Has anyone been appointed as a curator for your property and finances?**

Yes No

If Yes, please add their full contact details to page 10

If No, would you like to discuss this?

Yes No

11. **Do you want to be buried or cremated?**

Buried Cremated

Do you have any arrangements in place?

Yes No

If Yes, please provide details

12. **If it were possible, would you wish to donate any of your organs?**

Yes No

In the case of cornea and some other tissue, age does not matter. For other organs it is the person's physical condition, not age, which is the deciding factor.

If Yes, you will need to get signed up to the NHS Organ Donor Register. You can do so at www.organdonation.nhs.uk or by calling the NHS Organ donor Line on 0300 123 23 23 (lines open 24 hours, 365 days a year).

If you would like help with this please talk to your healthcare professional.

Cardio Pulmonary Resuscitation (CPR)

CPR is an emergency treatment which tries to restart a person's heart or breathing when these have stopped suddenly. Sometimes the media present CPR as being very successful. In fact when people have very serious illnesses very few who receive CPR will recover enough to leave hospital.

We would like to discuss resuscitation with you and your family. It can be stressful so please be aware that you do not have to discuss it if you do not wish to. However we would find your views very helpful.

The ultimate responsibility for making decisions about CPR rests with the Consultant (in hospital) or your GP (at home or care home). If CPR is not appropriate this will not prevent you from receiving other treatments for your comfort and dignity. These would still be offered to you as appropriate.

Would you like to talk to someone who could give you more information about CPR?

Yes No

Advance Decision to Refuse Treatment

An advance decision to refuse treatment (ADRT) is a legal statement to refuse certain treatments such as ventilation or blood transfusions.

Do you already have an ADRT? Yes No

If Yes, who has a copy? _____

If No, would you like to talk to someone about this? Yes No

Any other information

Is there anything, not previously mentioned, that you would like to make known and write here?

Yes

No

If Yes, please provide details

When you are satisfied with the information that you have recorded in this booklet, please sign and date below:

Signature:

Date:

It is important to remember that you can review your preferences and change your mind at any other time. If you would like to add to or review anything you have already written, please record it here and date it.

Review from page(s): Signature:

Date:

Review from page(s): Signature:

Date:

Review from page(s):

Signature:

Date:

Review from page(s):

Signature:

Date:

Review from page(s):

Signature:

Date:

Review from page(s):

Signature:

Date:

Review from page(s):

Signature:

Date:

Terms explained:

Advance statement: This is a statement of wishes, preferences, values and beliefs. It is useful when taking into account 'best interest' decisions on behalf of someone who lacks capacity, but is not legally binding.

Advance decision to refuse treatment: This is a decision to refuse treatment. It must be in writing if it relates to life sustaining treatment, signed and witnessed. This was previously known as a Living Will.

Best interest: If you lack capacity to make a specific decision and this needs to be made for you, any decision made must be in your "Best interests". This does not mean the same as what is in your best clinical interests. Rather the decision maker should take into account:

- **Your past and present wishes and feelings.**
- **Your beliefs and values that may have influenced the decision being made, had you retained capacity.**
- **Other factors that you would be likely to consider if you still had capacity.**

If it is practical and appropriate the decision maker must consult others including your family, friends and carers about your wishes and feelings, beliefs and values.

Curatorship: This allows a person to be appointed by the Royal Court to manage your property and finances.

Contact information

Your details

Name:

Address:

Postcode:

Telephone:

Mobile:

The person who knows you well

Name:

Address:

Postcode:

Telephone:

Mobile:

Your next of kin

Name:

Address:

Postcode:

Telephone:

Mobile:

Your Curator

Name:

Address:

Postcode:

Telephone:

Mobile:

Your G.P.

Name:	
Address:	
	Postcode:
Telephone:	Mobile:

Your District Nurse (FNHC)

Name:	
Address:	
	Postcode:
Telephone:	Mobile:

Your Specialist Nurse

Name:	
Address:	
	Postcode:
Telephone:	Mobile:

Your Hospital Team

Name:	
Address:	
	Postcode:
Telephone:	Mobile:

We would like to share this information with those contacts you have listed, do you agree to this?

Yes No

Signature: _____ Date: _____

*Adapted and reproduced with
the kind permission of
St Christopher's Hospice
London, 2010*
www.stchristophers.org.uk