

Advanced Care Planning (ACP)

Planning ahead for your future treatments and End of Life care issues

Over the last two years, we have held the following **Advanced Care Planning (ACP)** Workshops:

1. Forms to complete
2. Resuscitation
3. 'A Good Death'
4. 'Where do people die'
5. 'How to start that difficult conversation'



Advanced Care Planning covers three main aspects as you can see below:

Advanced Care Planning

Statement of Wishes and Preferences

- What you wish to happen
- Not legally binding

Advanced Decision to Refuse Treatment

- What you DO NOT wish to happen
- Legally binding

Lasting Power of Attorney

Who will speak for YOU

Why is it important to plan?

Serious illness and ageing can bring challenges many people prefer not to think about. At the same time many people fear the loss of control about decisions relating to their care. Research has shown that not many people feel confident discussing their wishes and preferences regarding 'end of life issues' i.e. how and where they would like to be cared for and be with their loved ones. Talking about death remains a taboo for many in our society.

To help facilitate discussions and break down some of the barriers about 'death and dying' we decided to start the **Advanced Care Planning Workshops**. From February 2015 to January 2017 Dr Ellen, Rika Adams and Pam Alcorn planned monthly Advanced Care Planning workshops. Most were held upstairs in the Palmer Room at our Health Centre and we also used Sonning Common's Village Hall to allow for easier access. We also spent a lovely afternoon with the ladies from the Peppard W.I. in the Peppard Memorial Hall.



We wanted our workshops to be welcoming and relaxed, by offering tea, coffee and some cake to make it more a 'café -style' environment; a place to talk and share thoughts with each other. Patients from Sonning Common mainly came to these workshops, but also from further afield, as we advertised in various newsletters. On average nine people attended each of the workshops.

During these sessions we covered:

- The principles of Advanced Care Planning
- Advanced Directives (formally known as 'Living Will')
- Power of Attorney
- DNA-CPR or Do Not Resuscitate and the 'Message in a Bottle Scheme'
- Communication Skills

- Where to get help/Local Contact List

You can read more about these subjects by clicking on the individual link on the advance care planning page of our website. For more detailed information, there are FREE books and leaflets available, please ask at reception.

Books, both by MacMillan:

- 'YOUR LIFE and your choices: PLAN AHEAD'
- 'End of Life: a Guide'

NHS booklet 'Do Not Attempt Cardiopulmonary Resuscitation decisions'

Other Leaflets:

- Local Contact List (of the relevant organisations in Sonning Common area)
- Bereavement Guidance (for our patients and their relatives/carers by Dr Ellen)

Websites:

- '**Dying Matters**' www.dyingmatters.org. A very informative website, where you can read a variety of related subjects, see video clips and download leaflets for free.
- '**Compassion in Dying**' www.compassionindying.org.uk. Very useful practical information.
- **ADA** (Advance decisions Assistance) www.Adassistance.org.uk. You can get help from them about making decisions in advance.
- **Sonning Common Health Centre's** own website www.sonningcommonhealthcentre.co.uk. This has more detailed information on the right side of home page under Advance Care Planning.

1. Statement of Wishes & Preferences

Let us explain first about the '**Statements of Wishes and Preferences**' (also known as 'preferred priorities for care'), in other words: *what you wish to happen*.

In this document you can include your wishes regarding:

- Your choice of place where, if possible, you would like to be cared for
- Where you would like to die (i.e. at home, in hospital, in hospice, nursing home)
- How you like to do things, any routines that are important to you e.g. shower or bath, number of pillows to sleep on etc.
- Concerns/suggestions regarding someone to look after your pet/your garden
- Your thoughts on different treatments; what is important to you
- Religious/spiritual needs
- The name of the person who will speak for you when unable to do so yourself
- Organ or tissue donation
- Your preferences regarding your funeral (you might like to plan your own)

You can use any note book to write your statement on, but if you would like it to be more structured please look at the document 'preferred priorities for care' at the back of the MacMillan book 'Your Life and Your Choices'. This statement is not legally binding, but it will be taken into account when anybody is trying to plan your care; to determine **your best interests in the event you lose capacity** to make decisions. You can change your mind/add or amend as you go along. It should be kept in a file that you and your family/carers can access when needed.

Please tell the people who will be involved in your care where the file is kept. If you like you can give a copy to your GP to go on your medical notes.

Unless people know what is important to you they will not be able to take your wishes into account.

Talking about death does not bring death closer.... it is about planning for life

2.

Advanced Decisions to Refuse Treatments (ADRT) (previously known as Living Will or Advanced Directive)

The Mental Health Care Act (2005) gives people a statutory right to refuse treatment through the use of an ADRT. This document sets out types of treatments ***you do not want*** to happen, **when you are unable to make decisions for yourself** in the future and the circumstances in which the refusal applies e.g. you may write:

'I wish to refuse antibiotics in the event that I have a severe chest infection that might threaten my life.'

OR

'I wish to refuse Cardio Pulmonary Resuscitation (restarting my heart/breathing) in the event that I have a cardiac or respiratory arrest.'

You should write in which circumstances you like to refuse the specific treatment and, if it relates to **refusing life sustaining treatment** (e.g. ventilated by machine or artificial feeding by tubes), it must include the statement **'even if my life is at risk'**.

Decisions must be made in advance when you are able to do so, i.e. you need to have full capacity so you are able to understand the consequences of your decision. It only comes into effect when you lose capacity. It is **legally binding** if 'valid' and 'applicable to the circumstances' and meets the requirements of the Mental Capacity Act. It must be in writing, witnessed and signed.

You **cannot** use an ADRT to:

- Refuse basic nursing care, to keep you comfortable, (e.g. washing, keep warm)
- Refuse offers of food and drink by mouth
- Request a certain treatment
- Request anything that is against the law (i.e. assisted suicide)

3. Lasting Power of Attorney (LPA)

You can choose a person (Attorney) to make decisions on your behalf when you are unable to decide for yourself. This person (or two different people) may make decisions regarding your:

- property and affairs
- your personal welfare

These legal documents (one for property and a separate one for welfare) must be in a prescribed form and has to be registered with Office of Public Guardian (www.publicguardian.gov.uk). It may take up to three months to get it registered and costs around £82 for each LPA (a reduction and/or exemption is possible).

It is possible to create your own, i.e. download forms from the internet, but it is not an easy task. Organisations such as AGE UK and Citizen's Advice offer help. You can see your solicitor and they will ensure that all legal requirements are met, but that is more expensive.

NOTE: If you have made an Advanced Decision to Refuse Treatments (ADRT) before appointing a Health and Wealth Attorney (LPA) in which you give someone else the power to refuse medical treatments on your behalf, your ADRT becomes invalid!

4. RESUSCITATION and DNA-CRP (the Purple form)

DNA-CPR stands for DO NOT ATTEMPT CARDIO PULMONARY RESUSCITATION or in short 'Do Not Resuscitate'

CPR stands for Cardio Pulmonary Resuscitation. This is a way to **restart the heart and breathing** when they have stopped.

What is likely to happen with CPR:

- repeatedly pushing very firmly on the chest
- using electric shocks to try to restart the heart
- 'mouth to mouth' breathing, or
- inflating the lungs through a mask over the nose and mouth or
- tube inserted into the windpipe

Chances of survival, will depend on:

- why your heart has stopped
- any illnesses or medical problems you have or had in the past
- overall condition of your current health
- how soon after your heart stopped the CPR was started (with every minute delay the survival drops by about 10%)

Possible risks, even if revived, are:

- fractured ribs or punctured lung, especially for older frail people
- you may need long term intensive medical care
- some people have brain damage or go into a coma

When CPR is done in hospital the outcome is successful in 10-15% cases. But anywhere in the community survival is more likely in the order of 5%. With serious underlying illness there is even less chance of survival.

In an acute situation, if there is no Do Not Resuscitate - form in place, the medical team will automatically try and restart the heart/do the best they can to 'revive' you. But in patients who are very ill it might not be appropriate to offer CPR, in which case the most senior health care professional will decide what to do in that situation. Doctors are being asked to discuss their decisions with the patient, family and carers where possible.

Your age or disabilities do not affect the decision, your current state of health that is most important.

If you do have a DNA-CPR form (purple form) in place then the medical team will not attempt to restart your heart. They would '**allow for a natural death**'. But having purple DNA-CPR form in place does not mean you will not get all other care and treatments, i.e.

- your pain will still be treated
- appropriate treatments will be given, i.e. infections will be treated.
- you will be given food and drink
- And any other care and comforts / support as needed

The **purple** form needs to be completed by the doctor, or senior health professional, signed and dated kept in a place that family also know. A tear off slip can be put into the 'Message in a Bottle' to advise where the form is kept.

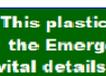
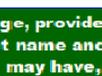
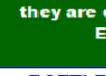


Southbourne Lions
**MESSAGE IN
A BOTTLE**



EMERGENCY INFORMATION SCHEME

THIS SIMPLE IDEA COULD SAVE A LIFE -YOUR LIFE!

	Complete the form and put it in the bottle	
	Put the bottle into your fridge	
	Place one green sticker on the inside of the front door	
	The other sticker goes on the fridge door	

This plastic bottle, kept inside your fridge, provides the Emergency Services with a contact name and vital details of any illness or allergy you may have, if they are called to an emergency involving *YOU*. Essential for anyone living alone

BOTTLES ARE AVAILABLE FREE OF CHARGE

**from Doctors' Surgeries,
Lions Clubs and many other places.**

Message in Bottle Scheme. These 'bottles' are for keeping important medical information and are kept in the fridge, so that Ambulance staff can find this information. Everyone who wants one of these can collect a FREE 'bottle' from reception

4. 'WHAT IS A GOOD DEATH?'

At our workshops we asked people to think about; 'WHAT IS A GOOD DEATH? Each group came up with answers like:

- pain-free
- with dignity,
- spiritual/religious needs met
- quick, in sleep
- with family
- cared for and die in place of choice (home/hospice/hospital)

We compared the place of death figures from the National Statistics with our local Sonning Common figures. The table below shows us the statistics for the years 2013 to 2016.

Where do people die?	National	SCHC 2013-14	SCHC 2014-16	SCHC 2015-16
Hospital	58%	39.8%	38.5%	27%
Home	18%	23%	14.5%	19%
Care Home	17%	24.5%	35.8%	35%
Hospice	4%	11.5%	11.1%	17.6%
Elsewhere	3%	0%	0%	1.4%

5. Communication Skills ('How to start that difficult conversation')

Talking about death and dying is still a difficult and an emotional subject for many people, but research shows that people often feel relieved after they have talked about death and dying with their loved ones. 82% of people have strong views of their End of life Care. Yet only 4% have recorded their wishes in a legally binding way and only 51% are unaware of partners End of Life wishes. This can make it very difficult for relatives to sort out the affairs at the (especially a sudden-) death of a loved one.

Why talking about dying is important?

- so that your family and friends know your wishes and needs
- you may want/need to discuss worries, fears or legal issues
- it will help relatives feel involved in your care when they know your wishes and decisions to refuse treatment for instance

When to start that difficult conversation

- anytime, but a prompt may be the death in family, friend or celebrity
- or at a deterioration of health

How to start that conversation e.g.

- "I know these things are not easy"
- "What is your main worry/concern on your mind?"
- "What is important for me to know, how can I help?"

What you can talk about e.g.

- "What special wishes/spiritual or religious needs do you have?"
- "How and where would you like to be cared for?"
- "Who would you like to care for your pets/dependants?"
- "Where can I find the information about your Will, Funeral plans, Organ Donation?"

"Talking about Dying will help to Prepare for a Good Death and Add Life to your Last Years"

"Telling our loved ones our wishes will help them have the confidence and comfort to know they are doing the right thing"

"How People Die Remains in the Memories of Those Who Live On" (Dame Cecile Saunders)

Matters of Life and Death Open Day

18th May 2016



On 18th May 2016, we held an open day at Sonning Common's Village Hall, called 'Matters of Life and Death'. 120 people came, despite the rain, to get advice and ask their questions from 17 different stall holders, who were all relevant to End of Life. The talks in the side room were also well attended and at lunchtime the Ukulele band played whilst people could enjoy some warm soup. All in all it was a really successful day!

Below is a copy of our programme, for your information.

Refreshments & Snacks Available

	Suggested Donation
Coffee	50p
Tea	50p
Cake	50p
Fruit	50p
Soup and bread	£1.00 (available 12 - 2 pm)



Enjoy your tea or coffee with a Game

- Circle of Life Game
- Conversation Game
- Go Wish Game

Thank you to all participants who made this day possible.
Hope you have a fantastic day.

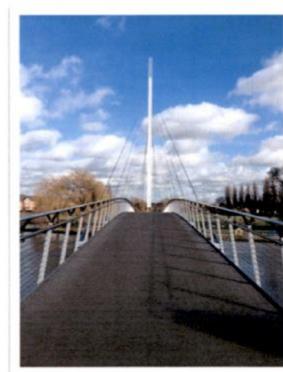
The organising team:
Ellen Kruidenier (GP End of Life Care Champion SE Oxon)
Pam Alcorn and Rika Adams (Practice Nurses)



Sonning Common Health Centre



Matters of Life and Death Open Day



Wednesday 18th May 2016
10 am - 4 pm

Sonning Common Village Hall
Wood Lane RG4 8SL



Sonning Common Health Centre



Programme

Talks and Workshops in the Side Room

10 am	Event Opening
	Dr Andrew Burnett, Senior Partner
	Sonning Common Health Centre
10.15 am	Sue Ryder - Introduction to Services & Staff
	Karen Guy Head of Clinical Services

Please visit our Stalls in the Main Hall

Advanced Care Planning	Practical information
Age UK	Practical and Emotional Help, Day Centres and Lunch clubs
Ambulance Service (SCAS)	Paramedics & Resuscitation

10.30 am	Wills, Lasting Power of Attorney and Probate Jack Bailey, Solicitors Blandy & Blandy	Befriending	Oxon Befriending for Life, Carers Oxfordshire, My Life My Decision & Sue Ryder Befrienders
11 am	Organ and Tissue Donation Rory Collier, Specialist Nurse	Cruse	Bereavement Counselling
11.30 am	Services of the District Nursing Team Elaine Cabbage and Sara Drake, District Nurses	Citizens Advice Bureau	Legal and Financial Advice
		Dementia	Dementia Advise
12-1pm	Benefits of Exercise and Healthy Living Sara Marsh, Wellbeing Workshop	First Responders	Role in the Community/Ambulance
		Fish	Support and transport in the Community
	<i>Susan Rusman and the Ukulele band members will play over lunch</i>		
2 pm	Sue Ryder - Introduction to Services & Staff Karen Guy, Head of Clinical Services	Funeral Directors AB Walker & Son Ltd	
		Gardeners	Nursing and Home Care
2.15 pm	Religious, Spiritual Need and Family Bereavement Ken Blanton, Sue Ryder Spiritual Lead	Message in a Bottle	Free Scheme to keep Important Information
2.30 pm	Cost of Care and Services in the Community Pat Gordon, Sue Ryder CNS & Trish Glynn, Wallingford EOL Community Matron	MND Association	Motor Neurone Disease
		Organ Donation	Organ and Tissue Donation
3 pm	Planning for Funeral Burial and Cremation Cynthia Townley, AB Walker & Son Ltd	Solicitors	Blandy & Blandy
3.30 pm	Mediation & Massage Mark Willis	Sue Ryder	Palliative Care in the Community
		Woodland Burial	Custodian Woodland Burial Ground

at Greys

6. 'SPECIAL' SESSIONS

From feedback, we found there was a need for more detailed information on some aspects of Advanced Care Planning. We therefore arranged four special sessions in the Village Hall. These were:

1. **Practical and Legal matters regarding End of Life**, presented by solicitors, including: 'Advanced Decisions to refuse treatments, 'Wills', 'Lasting Power of Attorney and Probate'.
2. **'First Aid for older People'** and **'Message in the Bottle scheme'**, presented by our local Community Responders.
3. **'Funerals, what are our choices'**, presented by Henley Funeral Director, Greys Woodlands Burial and Chrissie Philips.
4. **'Bereavement, Grief, Family Support and Befriending'**, presented by Sue Ryder Chaplain, Befriending Coordinator and FISH home visiting coordinator

The special sessions were very well attended - about 40-50 people came and found them most useful.

In January 2017 we held a more updated ACP information session with the WI at Peppard. We held our last workshop in the Village Hall, mainly for people with mobility problems so they could attend. On 1st March 2017 we supported Sue Ryder with their **'Matters of Life and Death'** Open Day.

Our Future plans

An Open Day for Public in Sonning Common's Village Hall on **Dementia in 2018**