



# Establishing End of Life Care & How to Support the Carer

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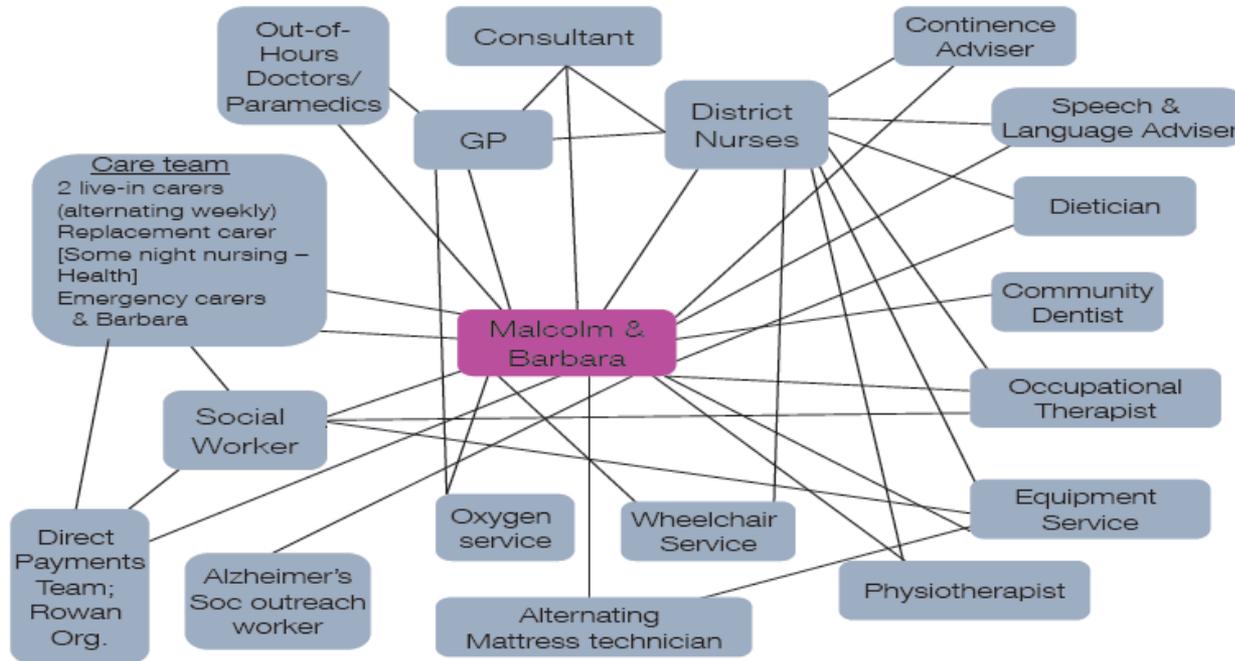


# May be boring but essential data!

- Carers '*provide unpaid support to a family member or friend and are a crucial part of EOLC*'  
*www.ncpc.org.uk*
- Currently 0.5 million people are caring for someone at the end of life (often a long time before also)
- >1/3 of carers provide >20 hours per week
- Carers should be supported – its not just the right thing to do but also helps them to care

# What can we do?

The national end of life care strategy clearly states support for carers should be provided at every step in the journey, given that the journey can be so complicated.....GP's are ideally placed for this:



# The National EOLC Strategy

Being a GP means we have an overview of the whole pathway and hence a unique opportunity:





# Key things to remember for Carers

1. Carers have their own needs
  - Initially recognising they are carers and how it impacts on their life
2. Carers are experts partners in care
  - How can we work together to best look after.....?
3. Need support in every setting
  - Focusing on increasing deaths at home has had an impact
  - Especially when changes in health/care needs occur
4. Carers need to be acknowledged into bereavement
  - Noted nationally to be a neglected area and see later links for more info on support that can be given
5. Caring shouldn't be a fight
  - Right information at the right time
  - Everyone involved with the persons care must clearly communicate with carers

# New ReSPECT Form

## What should happen to you in an emergency?

**ReSPECT**  
Recommended Summary Plan for Emergency Care and Treatment

**What is it?**  
The ReSPECT process creates personalised recommendations for your clinical care in emergency situations in which you are not able to decide for yourself or communicate your wishes.



**Who is it for?**  
Anyone may have a ReSPECT form, but it will have increasing relevance for people who have particular needs; for those who are likely to be nearing the end of their lives; or for those who want to record their care and treatment preferences for any other reason.

find out more at [www.respectprocess.org.uk](http://www.respectprocess.org.uk)

**ReSPECT** Recommended Summary Plan for Emergency Care and Treatment for: Preferred name \_\_\_\_\_

**1. Personal details**

Full name	Date of birth	Date completed
NHS/CHI/Health and care number	Address	

**2. Summary of relevant information for this plan (see also section 6)**  
Including diagnosis, communication needs (e.g. interpreter, communication aids) and reasons for the preferences and recommendations recorded.

Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). Also include known wishes about organ donation.

**3. Personal preferences to guide this plan (when the person has capacity)**

How would you balance the priorities for your care (you may mark along the scale, if you wish):

Prioritise sustaining life, even at the expense of some comfort	Prioritise comfort, even at the expense of sustaining life
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Considering the above priorities, what is most important to you is (optional): \_\_\_\_\_

**4. Clinical recommendations for emergency care and treatment**

Focus on life-sustaining treatment as per guidance below Clinician signature _____	Focus on symptom control as per guidance below Clinician signature _____
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Now provide clinical guidance on specific interventions that may or may not be wanted or clinically appropriate, including being taken or admitted to hospital +/- receiving life support:

**SPECIMEN COPY - NOT FOR USE**

CPR attempts recommended Adult or child Clinician signature _____	For modified CPR Child only, as detailed above Clinician signature _____	CPR attempts <b>NOT</b> recommended Adult or child Clinician signature _____
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# ReSPECT – more info

- Is a form of treatment escalation plan for those who are at risk of sudden deterioration and entering EOLC, which encourages conversations about preferences for care with patients and their families/carers
- **What is a ReSPECT conversation?**
- A ReSPECT conversation follows the ReSPECT process by;
  - discussing and reaching a shared understanding of the person’s current state of health and how it may change in the foreseeable future
  - identifying the person’s preferences for and goals of care in the event of a future emergency
  - using that to record an agreed focus of care as being more towards life-sustaining treatments or more towards prioritising comfort rather than efforts to sustain life
  - making and recording shared decisions about specific types of care and realistic treatment that they would want considered, or that they would not want, and explaining sensitively advance decisions about treatments that clearly would not work in their situation
  - making and recording a shared decision about whether or not CPR is recommended



# In Conclusion

- Carers need our support – think about the number of contacts we may have and make them count
- Make use of other resources
- Use the ReSPECT process to enable more honest discussions that are patient/carer led



# Useful Links

- [National Council for Palliative Care](http://www.ncpc.org.uk/)
- <http://www.ncpc.org.uk/>
  
- [Dying Matters](http://www.dyingmatters.org/)
- <http://www.dyingmatters.org/>
  
- ReSPECT Process
- <http://www.respectprocess.org.uk/>