

# Illness planning

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<http://www.crugel.3x.ro/index.html>

# Background

- Dementia a terminal illness
- Rate of people dying at home in residential / nursing care has declined in last 15 years
- Broad expression of choice that, when dying , people would wish to die at home.
- Of course this can be challenged
- How many of you share that hope?

- Most with heart disease for example, want to die in A+E with a good fight being put up
- Home is fine but only if you are really dying
- But hospital is not fine and is associated with
  - MRSA CDif
  - A high rate of mortality in its own right
  - Distress and disorientation
  - Unfamiliar staff

# The problems

- A perceived and right need to allow people to die, especially in nursing or residential care rather than going to hospital at the time of death
- A fear by home staff that they may be criticised for not sending patients to hospital
- A reluctance by GP's especially out of hours to take the risk of doing this.
- An inability by A+E staff to be confident of services in homes so that those who cannot be really helped are sent home.

# What is needed

- An ability to feel confident that staying in a nursing home can
  - Provide a better quality place to die
  - In fact often be associated with survival rather than death
  - Not be automatically criticised as a less good option
- Discussion with home staff, GP and carers that in fact, hospital is worse than care in the home
- Good skills

# Preferred priorities of care

- Was preferred place of care
- Now priorities to enable a broader discussion.
- Part of National End of Life Care programme

The Preferred Priorities for Care (PPC) is a document that individuals hold themselves and take with them if they receive care in different places. It has space for the individual's thoughts about their care and the choices they would like to make, including saying where, if possible, they would want to be when they die. Information about choices and who might be involved in their care can also be recorded so any care staff can read about what matters to the individual, thereby ensuring continuity of care. If anything changes, this can be written in the plan so it stays up to date. It is never too early to start a PPC plan particularly for residents in care homes, which for many is their permanent and final place of residence. The PPC provides an opportunity for care home residents and staff to work together to develop Advance Care Plans in accordance with the new Mental Capacity Act. Residents can initiate the PPC at any time and this will help staff follow their wishes and act as an advocate if the resident loses capacity towards the end of their life.

For more information, visit: [www.cancerlancashire.org.uk/ppc.html](http://www.cancerlancashire.org.uk/ppc.html)

## •Key points

It is never too early to start a PPC plan particularly for residents in care homes

Opportunity for care home residents and staff to work together to develop Advance Care Plans in accordance with the new Mental Capacity Act.



# But may not be enough

- **Specific discussion are needed on**
- DNR;- which in this circumstance is an almost universally irrelevant discussion as virtually no-one in a nursing home has a cardio-respiratory arrest
- Complex treatments that are especially burdensome such as Cancer chemotherapy or Complex surgical procedures
- **Use of Acute hospitals**
- Injuries such as fractures
- Illness such as chest infections
- Dehydration occurs and is causing the patient to suffer
- **Terminal care**

# The GCHIP

- Greenwich contingency Plan for illness
  - Developed by GP, nursing Home staff, old age psychiatrists and also carers groups
  - Sets out decisions that may be considered.
  - Gives explanatory notes
  - Asks GP/ Staff to make the decision
  - Requires and promotes discussion with the carers
  - Asks carers to signal their agreement or otherwise (or patients if they have capacity)

# Why take that approach

- As carers and patients rightly have a strong emotional attachment to their life and
- They therefore require, just as with DNR professional to advise on what treatments and styles of treatment are likely to work, benefit etc.
- But to be informed of this so that they can question it.
- The alternative is to make them fully responsible for all decisions which
  - Is a cop out for doctors and nurses
  - Places a large burden of apparent responsibility upon them, while not really giving them any control etc

# Experience so far

- Carers thought the form was sensible and agreed strongly with the principle.
- Used in several nursing homes and thought to be useful by patient and carers
- Following its use some have been cared for successfully at the home till they die, even though this seemed difficult and staff were anxious initially
- Others still went to hospital!