What do the 5 Priorities for Care of dying people mean for the care of people with dementia?

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Dementia “i” statements

• I was diagnosed in a timely way
• I know what I can do to help myself and who else can help me
• Those around me are well supported and are in good health
• I get the treatment and support, which are best for my dementia, and my life
• I feel included as part of society
• I understand so I make good decisions and provide for future decision making
• I am treated with dignity and respect
• I am confident my end of life wishes will be respected. I can expect a good death.
• I know how to participate in research
Easy to remember

D   Diagnosis
E   Effective post diagnostic support
M   Managing symptoms
E   Early identification
N   Non drug treatments
T   Treatment of medical conditions
I   Information
A   At, and towards, end of life
At, and towards, end of life

Available at www.dyingmatters.org

Tips

Reassurance: Offer kind words of reassurance bearing in mind that people are likely to be fearful of the future. For example:

“You can always revisit things, but because you’ve done that first step it will be a bit easier”

“Don’t be scared of planning ahead. It will make life much easier in the end”

“You need to be thinking about these things early on. You don’t need to be frightened. It’s much easier to do it earlier”

“Once you’ve spoken about these things, as hard as it might be, you can put them away and focus on enjoying things”

Speak early on “Too soon is never too soon”

But don’t despair if you haven’t. It can still be possible to communicate with someone about their wishes as their dementia advances, given the right situation and approach.

Things aren’t set in stone: Conversations can be revisited

It’s a process: Discussing the future and end of life is an ongoing conversation
ONE CHANCE TO GET IT RIGHT

Improving people’s experience of care in the last few days and hours of life.

Published June 2014 by the Leadership Alliance for the Care of Dying People
Priority 1

The possibility [that a person may die within the next few days or hours] is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.
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What is unique/special/different about dementia?

Clinical signs
Mental Capacity
Advance Care Plan
Lasting Power of Attorney
Five principles

Assume capacity
Best interests
Choose least restrictive
Decisions that are allowed
Ensure all steps taken to help
Priority 2

Sensitive communication takes place between staff and the dying person, and those identified as important to them.
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Maintaining communication even if in doubt
Non verbal communication important
People can express themselves despite severe dementia
Priority 3

The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
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Involve as far as possible
Often a longer period of adjustment
Role of care workers
Priority 4

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
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Carers can have had the role for some time
Priority 5

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.
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Carers must be involved
Pain/distress/behavioural changes
Food/drink/spiritual needs are the same
Dementia Revealed
What Primary Care Needs to Know
A Primer for General Practice

Prepared in partnership by NHS England and Hardwick CCG with the support of the Department of Health and Royal College of General Practitioners

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July 2014

Key points:

End of life care planning is important in dementia.

Patients with dementia should be encouraged to express their wishes and have them incorporated into advance care plans.

Relatives of residents in care homes often feel guilty and distressed.

Bereavement reactions, following a death from dementia can be complex.
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- Disseminating the message
- Emerging importance of post diagnostic support and care planning
- Opportunities from the Enhanced Services
- The Care Act/Mental Capacity Act
- Integration pioneers/Better Care Fund/Parity of Esteem