

## Vulnerability & Dependency

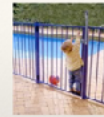
### Maslow's Hierarchy of needs



Maslow is well known for his hierarchy of needs, which develop as one matures, reaching the pinnacle in finding one's purpose in life. Some think in dementia the layers peel off and all that remains is the need for physical care - it is certainly important to provide care with respect and dignity when getting undressed or taking a bath or shower, ensuring hearing aids are working, providing safety, both protection and prevention of falls, fire, nutrition, finance and physical access, but these 2 levels alone do not represent sufficient good care.

Love and belonging remains an essential need, relationships can be encouraged and affirmed, dolls or pets appropriate hugs or touches. I heard of a care place that included these in the care plan. Self-esteem includes feeling valued, compliments on clothes, makeup, it is important always to make eye contact. Provide purpose, provide opportunity to be useful, ask us things, say thank you, make us smile even laugh!

## Meanwhile...



- ◆ Patterns from the past remain
- ◆ Purpose and hope
- ◆ Provide opportunities for joy
- ◆ Happiness might involve risk

End of life care is not just getting forms completed, it's an opportunity to get to know someone better, understand which past patterns can enable them to participate in today, and finding places and opportunities for joy and hope for the future. The Mental Capacity Act says decisions should take note of all options for Rx and previously expressed preferences so someone needs to have found out what these are and discussed them.

*Dr Jennifer Bute is a retired GP, diagnosed with dementia aged 63. She is a campaigner and regular speaker at events. Through her Christian faith she sees dementia as a Glorious Opportunity, while acknowledging the challenges it brings.*  
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One thing we all have in common is eventually we all reach the end of this life but there is no need to fear this, much can be done to plan ahead to ease the way. Long before we have difficulty communicating! Personhood doesn't change, feelings and emotions remain long after the ability to remember facts and tasks. This picture illustrates that it is possible to look in 2 different directions from the same stand point even assume others are seeing things the same way; just as assumptions are made about those living with dementia who may see things differently from those caring for them particularly concerning end of life issues.

It is very important to discuss these things as early as possible while everyone can understand fully the implications in honest preparation for the future.

For Christians who can be sure that Jesus has gone to prepare a place for them death itself is not to be feared but often the path there can be of concern for all parties so prepare!

## EOL choices

- Under what circumstances do you want .....?
- What treatment would you (not) accept?
- How can we add to your comfort?
- How would you like to be remembered?



### End of Life Wishes

These need to be clear. Often there are not simple yes or no choices.

*Do you wish to be resuscitated?* is not yes/no

*Under what circumstances do you wish to be resuscitated?*

*When do you not want to be given treatment?*

*What kind of treatment would you accept or not accept?*

### Pain management

*How would you like comfort to be managed?*

*Do you want to be bathed or helped to bath yourself and would you like bath lotions or background music?*

### How do you expect to be treated?

Are decisions in the future based on other peoples convenience or what make the person feel better.

### How do you want to be remembered?

Someone who loved, forgave, lived at peace, not just sitting around waiting to die. Why not ask us while we are able to discuss it?

Who is the person who knows you well enough to know how you would respond in a situation that you had not foreseen?

## Language

*The illness has replaced the person  
I love her just as she is now ( is this acceptance or denial?)  
He is not the same person ( a stranger not my father)  
I have got 2 children now ( still a member of the family )  
He follows me around like a dog ( is he treated just like a pet?)  
The real person died a long time ago ( what is left ?)*

Language used when talking about someone living with dementia is very significant.

*I hate this dreadful illness!* So has the condition replaced the person or disguised them?

*I love her just as she is now!* Can be acceptance but can sometimes cover up denial of progression

*He's not the same person, he's like a stranger, not my father anymore!* But he is and he needs to be found.

*I am back to looking after a child!* Well often children are given more tolerance and acceptance than someone with dementia

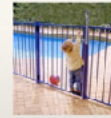
*He follows me around like a dog!* Is he treated same?

*The real person died a long time ago!* So what is left, just a clothed skeleton? It is not true that they died a long time ago, they are trapped inside the condition and no one has bothered to find them, it is like living in a foreign land, not being able to speak the language and everyone ignores you.

End of life care is an opportunity to get to know someone better, understand which past patterns can enable them to participate in today, finding places and opportunities for joy and hope for the future.

## Meanwhile...

- Patterns from the past remain
- Purpose and hope
- Provide opportunities for joy
- Happiness might involve risk



For many, childhood hymns and choruses can be comforting even if they no longer attend church. Familiar songs, even nursery rhymes can bring smiles. Many people with dementia feel abandoned and ignored when unable to communicate or help others to interact with them, to understand what lies behind their distress, to affirm them in their reality, and help them re-engage with the present, to smile again and feel joy. A person's needs are not just physical, there are spiritual needs too.

### Their Present is our choice

- are we Living or Dying with Dementia
- Enable or Disable
- Purpose & Joy



We can find peace and purpose even in later stages of life. We can be enabled to live with dementia until we die. It is a joy to see faces

wreathed in smiles and know one has contributed to this. We are still there and can still be found. We are still precious to God, one day will be complete again, but help us feel we still have worth here!