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PLANNING AHEAD FOR A GOOD DEATH

This information comes from the book "Letting Go. How to plan for a good death" by Dr Charlie Corke, Scribe Publishing. 2018 (218-228)

What are the treatment options? Is there anything else?
This question expects all the possible options to be presented, and signals that you don't want the doctor to select only his (or her) choice.

What are the benefits and harms of each? How likely are they?
This invites a risk-benefit assessment of each option. It encourages a partial assessment of each option. This forces the focus well beyond the 'you need an operation' approach.

How do you rate my chances of a full recovery? What happens otherwise?
This is a very important two-part question, especially when full recovery is an important goal (as it often is). It establishes the chance of full recovery and identifies what the alternatives might look like.

Is there more information that you think I should know?
Good medical practice involves sharing all the 'material information' required by the patient to make a fully informed decision. This question makes it difficult for the doctor to unilaterally decide not to mention some options.

What does my future hold? What happens with this disease?
This invites honest explanation of the likely course of disease; it identifies what is likely to happen. Knowing this is important, because these things inform the cost-benefit assessment.

What will happen if I don't have this treatment?
Decision-making depends on having full information. Understanding what *not* having treatment means is as important as understanding the implications of having the treatment. In serious illness, the implication of no life-saving treatment is often death. It is important that this is recognised.

What do you recommend? What would you do if you were me? Why?
This is a powerful question that can often be very revealing. Many doctors find it confronting. It asks them to combine the medical reality (of the disease and treatment) with a personal perspective and significantly your priorities ('if you were me'). A thoughtful answer to this question can resolve the difficult task of balancing risks and benefits.

Asking 'why' provides a check to see with factor(s) the doctor has given most weight to n coming to a conclusion. It provides a check that the things that the doctor has considered are those that are important to you. There is no obligation to adopt the doctor's choice, but the process can be useful and illuminating – and it might be the right answer.

Resources

Advance Care Planning Australia https://www.advancecareplanning.org.au/
This site provides information about advance care planning, including information about how legislation and forms differ across the different states and territories.

MyValues https://www.myvalues.org.au/
MyValues is a free online program where a set of specially constructed statements are presented that help you identify, consider and communicate your wishes about how far you would want to go with medical treatment in the later stages of life. It constructs a profile that explains your values in relation to life, death, and medical intervention. Understanding your values will help your doctors and your family to make better choices about your medical treatment.

Dying to Talk http://dyingtotalk.org.au/
Dying to Talk encourages people of all ages and levels of health to talk about dying. Despite being something that touches everyone, death doesn't receive enough visibility. Dying to Talk aims to reach into the community to normalise dying and to help people to work out what's right for them at the end of their lives.

The 'Dying to Talk Discussion Starter' guides you through talking with your loved ones.

Death Over Dinner http://deathoverdinner.org.au/
Conversations about end-of-life care often take place at a hospital in the midst of a crisis. Many people die in a way they wouldn't choose, with loved ones left feeling guilty, bereaved, and anxious.

This program encourages people to organise a dinner with the express aim of getting people to talk about death – to, as they put it, 'participate in the most important dinner conversation Australia is not having'.

They provide a range of videos, reading, and support materials, as well as giving tips to get the conversation started. The party host chooses the guests and the menu, and then lets the wine and conversations flow. It's a nice approach.

Death Café http://deathcafe.com/
A Death Café is a discussion group, where there is a directed discussion of death with no predetermined agenda, objectives, or themes. The aim is to encourage thought without leading people to any conclusion or course of action.
Food again plays an important role – and cake may feature. It's another excellent idea.

Barthel Score: The **Barthel Scale/Index (BI)** is an ordinal scale used to measure performance in activities of daily living (ADL). Ten variables describing ADL and mobility are scored, a higher number being a reflection of greater ability to function independently following hospital discharge. Time taken and physical assistance required to perform each item are used in determining the assigned value of each item. The Barthel Index measures the degree of assistance required by an individual on 10 items of mobility and self care ADL.
Intended Population : Patients with stroke, patients with other neuromuscular or musculoskeletal disorders, oncology patients.

ABC podcast 'The Pineapple Project' Season 4: Death

https://www.abc.net.au/radio/programs/the-pineapple-project/episodes/

Traffic Light (Setting up awareness and agreement in advance)

GREEN
• Excellent recognition • Can walk (with or without sticks) • Can control poo and wee • Can do Activities of daily living (Barthel score above 90) • Food: able to eat, drink and enjoy it. • Life: can enjoy life, ie happy, laugh, make plans can tell jokes feel involved and have meaningful interactions with people. • Can make and enjoy music. • Knows all family and friends, ie full recognition. • Saying “Yes” to invitations. • Mood is good, minimal anxiety and/or depression. • Good energy, sleeping well. • No pain, or if there is pain, it is well controlled by medication.

AMBER
• Communication issues, difficulty talking but can understand still. e.g can still laugh and listen to music but can’t make music or jokes any more. • Repeating self a lot. • Forgetting things/memory lapses. • Sometimes recognises family and loved ones, sometimes not. • Difficulty walking with aides but can use a wheelchair if someone pushes. • Can do some Activities of Daily Living but most of the time needs help (Barthel’s score 20-90) e.g needs help with eating, dressing, showering, personal hygiene of varying degrees. Can still enjoy eating food but needs help and can’t cook. • Intermittent catheterisation. • Not planning for the future, mood is up and down, more anxiety and / or depression. • Social withdrawal, saying “No” to more and more invitations. • Looks and feels tired and sick, not sleeping well. • Pain in body, or other physical symptoms, controlled by medications.

RED
• Can’t talk or communicate in any way, ie can’t express or understand communication. • No memory. • Can’t recognise family and loved ones. • Not engaged, not interested, can’t laugh, can’t listen to music, not “Dass Alto”. • Not able to move, bed bound • Permanent catheter for urine and nappies for poo. • Food: not able to eat or enjoy food. • Pain or physical symptoms not controlled • Totally dependent on assistance, i.e Not able to do any Activities of Daily living