Rehabilitation in palliative care: what matters to patients?

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WAY IN
Everyone Welcome!
What’s important to people at the end of life?

• Receiving adequate symptom management.

• Co-ordination and continuity of care.

• Avoiding inappropriate prolongation of dying.

• A sense of control, achievement and self worth.

• Relieving one’s burden on others.

• Strengthening relationships with loved ones.

• Having an opportunity to say goodbye and bring closure.


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Where does rehabilitation fit in?

Enabling people to match their needs and goals and aspirations with their capabilities and resources.

- What do you need to do everyday?
- What do you want to do?
- What are your priorities? What matters to you?
Stories are not simply recounting ‘how it was’ – they are a way of presenting ‘how I want you to see it. The way we tell and hear stories is shaped by our individual preferences and experiences.

Everything has been arranged, from A to Z. I’ve had the funeral directors around and chosen my coffin. I did have one problem that was tricky – my mum and dad live 300 miles away from me and Graham, and it worried me: what’s going to happen if I get buried here – it’s too far for my mum and dad to come if they’re feeling they want to grieve one day and vice versa, Graham.
So although I didn’t want to be cremated, I will be, and one casket can be buried back home and one here...

I’ve got all of the practicalities sorted out, the hymns, the music, I’ve talked to the vicars about how I want the service. So if, God forbid, I take a turn for the worse, the i’s are dotted the t’s are crossed on what I want.
**Occupational therapist**

Gill remained incredibly positive ... she was holding it together because that’s who she is: a professional lady with a bright outlook on life.

**Social worker**

She’s very competent and resourceful ... she has overcome a lot of the problems herself ... she won’t sit there feeling sorry for herself.

**Palliative care specialist nurse**

Gill’s a great initiator ... knows how to take things forward ... you don’t wait around for people to do stuff for you, you get on and do it yourself.
Gill went home adamant that she wanted to be upstairs, which we completely went with because that was her wish. The bath was highly important to her and there was no way of having a bath downstairs, and she felt that was a better option.
I had a happy childhood. I’d go watch the blacksmith pump his bellows when I was 7. I learned so much that when I got a job at the factory at 14 I knew more than the other young starters so I did really well. Fortunately I met a good gang of kids. The chaps at work, I always met the best ones. I don’t know why, but everything seemed to work out right for me. A friend of a friend in the merchant navy helped me to get a job there. The blokes on the ship were really good fellows, took care of me. I’ve been to practically every country in the world.
Three o’clock this morning, I’m wide awake and my head’s going round and round …

How am I going to get my rice pudding from the kitchen to my table?

I’ve got this tea trolley I made years ago. It’s got four wheels but if I take the back two off, build it up with a bit of wood, like, so it doesn’t slide. There’s plenty of timber down the shed. And I’ll put on handles, screw them into the side, I can hold on and walk round with my tea trolley, push, stop, push, stop, like so. I’m looking forward to going home. It’ll be an adventure!
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At first, he was realistic, saying he didn’t think that he would cope at home.

But he didn’t improve much with radiotherapy and he got more and more frustrated with us saying you’re not ready to go home. The more we talked to him the less he seemed to understand what we were getting at, that he wouldn’t go back to how he was.

Eventually, we said you’ve got options: go home as you are but agree not to undertake any kitchen activities.

He said he just needed a rail on the work surface, things that we thought weren’t so appropriate because work surfaces aren’t meant for such weight bearing activities.
We had to be quite assertive with him to make him understand where we were coming from and why we were saying what we were saying and that it wasn’t to take away his independence.

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And when we want your opinion, we'll tell you what it is!

Federation of Charities for the disabled

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Where does rehabilitation fit in?

What do you need to do everyday?

What do you want to do?

What are your priorities? What matters to you?

Enabling people to match their needs and goals and aspirations with their capabilities and resources

Overcoming the environmental and attitudinal barriers that prevent participation
How do people with advanced cancer experience disability?

ACKNOWLEDGING PROBLEMS
- Exploring boundaries
- Concern about dependence
- Reordering and restructuring
- Seeking information

MANAGING THE TENSION
- Twin-tracking
- Response shift
- Finding possibilities
- Demarcating safe spaces

NOT ACKNOWLEDGING PROBLEMS
- Asserting normality
- Resisting a ‘disabled identity’
- Claiming competence

I’ve had to give up my vegetable garden, which makes me feel sad. I can’t stand and move without a walking frame anymore. But I have two or three ambitions that I will achieve. Not a question of wanting to, I am going to achieve them. And the first one, it is the essence of being independent and standing alone, is I want to go and hit a golf ball. Proper swing, unaided, followed by a hole.
What enables us to live well?

- Cognitive strategies
- Psychosocial maturity
- Social attractiveness
- Self-esteem and self-efficacy
- Hope and faith
- Luck, timing and/or context
- Absence of risk factors and presence of protective factors
- Temperament
- Ability to internalise social supports
- Ego mechanisms of defence
- Social supports
- Attributional style
- Psychosocial maturity

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The lecture you gave was not well received.

Boring

Rubbish

I want to kill you
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‘Listening generously’

• What is this person telling me about what’s significant and important to them?

• What does this represent to this person?

• What is the person saying about their sense of themselves?

• What does this say about their hopes and expectations for the future?

• What are my assumptions and beliefs about what’s realistic and possible here?

• How is my attitude affecting what I hear and how I respond?
Irene and I have always been great caravanners. I don’t want the bother of a caravan any more, so I’ve just recently bought myself a camper van, which means that Irene and I can still go away for weekends.

I’m organising some modifications for it: I’m going to sort out power steering, and I’ll have one of those knobs on the steering wheel, like the old truck drivers used to have, that should sort it out. I believe I’ll have enough movement in my feet to operate the clutch. I think that should work, don’t you?
“The most valuable outcomes of rehabilitation might be] possibilities or ‘feasibilities’ rather than specific achievements.”

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Keeping a focus on both life and death