

It's your future...and allied healthcare professionals are here to help you make everything of it that you can

So, the diagnosis is brain tumour.

You won't know what the name or grade of it is until after the surgery whether that be biopsy, debulking or resection. The diagnosis remains brain tumour and things are changing.

First hit - the words 'brain tumour'. And then come the questions. What do you mean I cannot drive, how can I live this life I lead without driving? What should I tell the family? How long have I got? What did I do to get it? What should I have done to prevent this happening? Shall I alter what I eat - will that change things? Is it inherited? I should not have lived so close to those pylons; this is my phone use isn't it?

Then comes the plethora of medical language and unpronounceable drugs to prevent this, manage that. They just roll off the tongues of the professionals. It is impossible to remember what they are, least of all what they actually do. Go with it!

You feel fine so why are you going in for surgery? Feeling this good surely means there is nothing wrong and you can just leave here. But the surgeon says not. Your family say not. You know deep down inside not. So you go for it. The reassurance of knowing you are having movement or language monitored for the surgery helps. The professionalism of those around you helps but this path is rocky. You search for the old path, the smooth path, the busy-with-the-day-job path, enjoying-the-family path, planning-the-next-holiday path.

Yay, you did it! You woke up from surgery. This drink is perfection; nectar from the Gods. What is for tea? And then the 'what next' question creeps up behind you or is thrown casually into the arena by that lovely visitor who brought the chocolates.

The 'next' is going to be about getting home and facilitating living to enable coping and enable coping to facilitate living.

If you define living as 'the way in which you live your life' and coping as 'to face and deal with challenges successfully in a calm or adequate manner' then this is what we do when we enter the 'what next' phase. Whether this is more oncology treatment, rehabilitation or just being home.

You do not have to take this path alone. There are allied health professionals (AHPs) with a wide variety of skills, knowledge and approaches to facilitate you coping with living and living with coping. They will work with your goals so that you are the empowered one and you can do as much as is possible given the extent of the problem you are facing. Our best is what we can do within the constraints of the situation we are in at this moment in time. That is all anyone can expect of you. That is what we, as AHPs, are here to help you achieve to the extent you want.

The AHPs officially include: physiotherapists, occupational therapists, speech and language therapists, clinical psychologists, dietitians and pharmacists and their support workers. They are integral to your support network along with neuro-oncology clinical nurse specialists and the various charitable organisations. Each help you to be how you want and need to be.

These people are going to help you through the 'next' - however long.



Helen Spear

Speech and Language Therapist, North Bristol NHS Trust and a member of the Community Therapists Network, United Kingdom. Helen works in the specialist area of neuro-oncology.

E: hespear100@gmail.com

Day by day. Week by week. You become the expert in your tumour. The AHPs are there to help when you need advice to help you maintain the expertise:

Your sight. You can see most things. The world looks good apart from that bit to the side, or the need for the patch because seeing two of these worlds is headache inducing.

Fatigue. That treatment was exhausting. How will I manage tomorrow and forever like this?

That leg, that arm, that clumsiness. I want to do so much. How do I manage? Are there exercises I can do? Are there systems that can be put in place so that I can do as much as I can, just by myself?

Talking. Why can't I remember that word? If they would just shut up so I can think of it. I could say something funny now but it won't be quick enough to make the impact. I want to soothe them but the words aren't there. What are they saying? My brain didn't compute that instruction; should I guess at what I should do but risk looking daft?

Memory. I know someone is coming today but who was it? I think I have read this page before but I cannot remember. Where was I in making a cuppa? Was I making a cuppa?

Reading. It doesn't make sense. I was so into my books. What will I do now that I cannot read? I cannot stand all the rubbish on the TV.

Writing. I can read it but cannot write it. There must be a way.

The list of changes that can happen is longer. Someone is there who can help. Ask.

The AHPs don't just sweep in and make it better. They aim to give you some control over what is happening. They aim to give you therapy, help, guidance, advice as appropriate. They listen. They get in tune with you and your personal needs. Experience of the condition in others they have worked with helps because things that have worked for others can be suggested.

But you are in the centre. This is your life-changing diagnosis. This is your future and the AHPs are here to help you make everything of it you can.

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