

The patient's journey through my eyes  
*by Chris Curtis*

Three words that change your life: 'I'm sorry to say that the biopsy shows that *you have cancer...*'  
It's the start of the Patient Cancer Journey.

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On a recent trip to Brighton, I needed to plan my journey. It was so easy. I just used Google. How I wish the cancer journey was that easy.

No matter how much the diagnosis of cancer may have been suspected, the sheer enormity of hearing that statement often results in gut-wrenching emotion and anxiety. The rest of the conversation often blurs into a nightmare of thoughts and fears and information overload. If this was a computer, it would freeze.

So many questions and thoughts, and disbelief. ‘What am I going to tell my wife/husband/partner/children? Why me? How did this happen?’. All these fill your mind as you try to rationalise what you are hearing. The medical and nursing team provide details of the cancer and treatment, but your mind hasn’t yet moved on. ‘I am going to die. God, it’s cancer.’

Now for your treatment plan: ‘Thirty-six days of radiotherapy, and you will need a mask making. Chemotherapy one day each week for six weeks, plus an operation at the end of it all. We will fit a feeding peg to help you maintain your nutrition intake and you will see our clinical nurse specialist, dietitian, speech therapist...’

Once the realisation hits home, there is often a feeling of isolation, despite the individual support of family and friends. Some people are fortunate to have lots of support, but this is not available to everyone. However, no matter the person’s age, social status or background, the basic support needs are often similar.

The diagnosis, subsequent treatment and its consequences all take their toll. The need for support is there at all stages of the process. Some people require support in the short term, during specific stages of this journey, whereas others require a much more prolonged service.

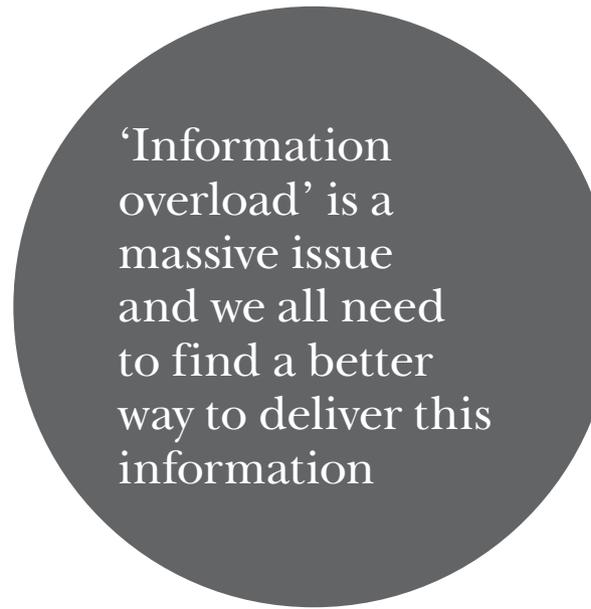
At its best, I truly believe that NHS cancer teams deliver a first-class treatment plan and treat every patient as an individual, not a number. They get to know the person and family, and work as a team to help get the patient through the treatment.

At the stage of diagnosis, the ‘information overload’ is a massive issue and we all need to find a better way to deliver this information.

One idea I have observed was, at the point of diagnoses, the oncologist recorded the various conversations and explained: ‘I will be telling you some news and will be talking about what happens next. As such, I record these conversations so you can take a copy home and listen to it in your own time, with your family and friends.’ So simple, yet so powerful!

**Dealing with survival**

I believe that where the NHS falls down is once you move on from daily, weekly or monthly visits with the team to living with, or beyond, cancer. It is like having a massive



rug pulled out from under you. The transition from treatment to living with an unknown future is scary and the thought of getting back to where you were before those three little words were said to you is not easy. ‘Yes, I have been cured of cancer. Happy days.’ Or is it?

Now I am in the ‘survivorship’ phase, what’s next for me? Questions, questions and more questions...

*Are these side effects normal? I’m feeling low and alone. Where do I go for help? What services can I access? What happens if I think it’s come back? Who can I talk to?*

Because medicines, treatments and the cancer team have all improved throughout the years, more patients are on the survivorship pathway, and that is to the credit of all the healthcare professionals involved. My thoughts are that the services currently dealing with all these survivors are under extreme pressure and, as such, some patients miss out on important and much-needed support.

**Planning for survival**

I thought it would be good to share with you some feedback from a recent visit to a cancer centre in the UK. I was invited to the centre to observe the multidisciplinary team (MDT) meeting and meet the team and patients in the clinic (Table 1), with the intention of understanding what planning takes place and how the healthcare professionals prepare to ensure the quality

Total reviewed for clinic	32 patients
Male	29 (91%)
Female	3 (9%)
Ages range	33–99 years

Table 1 Setting the scene at the MDT

delivery of both the treatment plan and the patient experience. My observations were through the eyes of a head and neck cancer survivor.

Owing to some of the complexities of patient selection, the MDT meeting over-ran but I must say that the last patient got just as much discussion time as the first. I now understand why clinics sometimes start late, and fully appreciate the reasons why. It should never be a lottery of who is first or last on the list, when it comes to the depth of discussion regarding the patient, just because the clinic may start late. At this meeting, every patient was important and worthy of discussion time, no matter how much the list was postponed.

Teamwork is a cooperative or coordinated effort on the part of a group of people acting together as a team or in the interests of a common cause. This MDT meeting showed teamwork at its *very best*; thank you for the insight.

The patient's journey begins...

In my opinion, the patient was put at ease by the oncologist introducing the various people in the room and explaining why they are present, and then talking to the patient about their life story. This opened up the patient, who starts to talk, and it can be seen that he is a little less frightened.

The oncologist explains the MDT – how it is a collective of specialists, what happened during the MDT and why it was so important in coming to the decision about his treatment pathway.

Positive observations

- When discussing the treatment plan and what happens next, the patient was under no illusions that diet and nutrition is very important to his/her recovery.
- The delivery of the news and treatment plan was excellent.
- The patient fully understood the importance of his/her own health. The role of drinking/smoking and why what to eat is so important going forward was emphasised. The past cannot be changed but the future can. It's 'your choice'.
- The availability of all the other related services in the clinic was great to see.
- The explanation of the radiotherapy mask was very good and to have one in the clinic was excellent.

What stood out for me

When I arrived at the clinic after the MDT meeting, I was expecting a slick operation and found a well-organised team ready to work together and deliver a first-class patient experience. As such, I was not disappointed.

I was impressed by the availability of all the main healthcare professionals at the clinic for patients to see on the same day and during same appointment. Each one, when called upon, reacted with professionalism and speed to help, support and advise accordingly.

I thought I would save the best till last. As discussed previously, recording the delivery of the news/diagnosis and treatment plan, and then offering a copy to the patient to review in the comfort of their home, is so simple and yet impressive. This will help with the patient experience, even if the patient at this point does not know what they will do going forward.

My time at the cancer centre has been most valuable to my work on the patient journey, and has given me a greater understanding of what happens from the healthcare professional's point of view.

I would like to thank all the team for making me feel welcome and allowing me to see the department running on a busy clinic day. It could not have been easy having a patient visitor, but not one person put any obstacles in the way of me observing and that is a credit to everyone.

My lasting memory of the day will be that any patient now or in the future could not be looked after by a better team.

What the oncologist said about my visit...

'It was a great pleasure to invite Chris into our MDT process. Patients are at the heart of what we do but very seldom do we invite them to see what we do. Having Chris brings his perspective to bear on our processes, and how they directly affect patients like him was a valuable insight. It is too easy for the process to obscure the patient with the problem and Chris allowed us to make sure we stay focused.

'Chris was able to give feedback on what we do well but also offer insight on how he has seen things done differently to good effect elsewhere; all of this is hugely valuable to service improvement. Having been a patient treated elsewhere meant that he could observe our processes objectively; he had walked to the same destinations as our patients, but by different roads.

'We introduced Chris to our patients and they were happy for him to be an accredited observer in our clinics, knowing that we are a team that wish to stay resolutely patient-centred.'



Mapping the patient journey  
I am looking to visit other cancer centres as a patient observer and find other good practices, understand how the patient journey differs from centre to centre, and then share my findings across the cancer centre network.

On a website designed and built by patients/carers, for patients/carers, I am mapping the patient journey through the eyes of the patient across all tumours, starting with head and neck cancer (Figure 1). The journey will be available on a dedicated website and will include patient videos, testimonials, thoughts, real stories and how the patient understands each step (Figure 2). Patients are being sought and asked to map their journey from discovery to diagnosis and beyond. The website will include health professional statements, written and filmed patient stories, plus lots of frequently asked questions. The website will also have a newsletter, research section and lots more.

I hope you have enjoyed reading this article by a patient. I would like to take this opportunity to personally thank Ajay Nigam, a consultant ear, nose and throat surgeon. His skill and knowledge is the reason why I can write this article; he is a true life-saver and my family will be forever thankful to him. I'd also like to thank Joanne Ashton, CNS, whose kindness, understanding and passion helped me come to terms with those three little words: 'You have cancer.' All the team at Blackpool Victoria Hospital were fantastic and I say: 'Thank you all.'

*Cancer is a long and hard journey, but you don't have to walk the road alone. You will meet many good people who are there to help and guide you on the way. They will find you when you are least expecting it!*

Chris Curtis, Head and Neck Cancer Survivor,  
Diagnosed Friday 13 May 2011



Figure 2 The patient journey website



The Swallows –  
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Figure 1 The patient journey