

The views of a person receiving care

Peter is a 42 year old man with quadriplegia. He was born with spina bifida and suffered a spinal injury after a fall at the age of 36. He has since retired from his job in a local council and has been a wheel chair user ever since.

Journey

Service Touchpoint

These comments and quotes from 'discovery interviews' with people receiving care, have been arranged in green boxes along the top and red boxes along the bottom and are aligned to the 'care journey' from when a person is first referred to the nursing team and until present day.

Red and Green does not mean the service was 'bad' or 'good' but rather that the comment was phrased negatively or positively. Some phrases can even be read as both e.g. "I think nurses are overworked" is a negative statement but shows the person's empathy and understanding for the service. Having a team discussion around:

- i) 'What this quote means to me is...', and
- ii) 'I think some opportunities for improvement in our team are...'

and then planning your next steps for improvement is the main thing.

A thought bubble (see below) has been placed at a few points to start your conversations off if time is limited. But it is best if team members take the time to read all comments and discuss the one or two that stood out to them and why [recommended workshop time 1hr].

Where a comment shows great evidence of one of the five principles of Neighbourhood Care, a blue diamond has been placed beside it (see below).


Neighbourhood Care Principle

Discussion point

b	Ref: NC			
	They moved my bed from one room to another so I can be involved in cooking and stuff. Little things like that have a great psychological impact.			
	Everything I have raised with my social worker in terms of my carer has been acted upon.		Streamline it as much as you can, people communicating with each other, being patient led (rather than fighting your corner) [between the NHS and carer staff] and just look after the patient, and look after their best interests. And I feel that to a degree is happening.	
	In terms of reducing the care package, that was a decision between us all. Again that was me *smiles* I've got a wee stubborn streak and I didnae want to be dictated to when I went to bed, you know...	My care review [social care] is every six months and relates to my feedback.	A lot of people took time, a lot of nurses took time (as they do to this day) to try and alleviate the fears as best they can.	Staff don't ever moan with regards to all that they have to do. I have no doubt that the care I received is person centred, but there's more and more bureaucracy that seems to be getting in the way and financially... I can only imagine how much I've cost the NHS! *smiles* They come in and I keep saying "how much am I costing you the day?" *smiles more*. There's a lot more pressure on all the services nowadays and we maybe feel it in this microcosm.
There had been two or three days of me feeling very unwell, I'm grateful to this day that she recognised the signs there and then and she basically saved my life at that point.	The more confident I got from that then I was starting to push myself a wee bit more, to end of corridors... and I was giving myself my own targets really to do that. They were allowing me a wee bit of 'carte-blanche' to do that. They supported me with fitness and weights and that kind of thing as well.	I know they have multi agency meetings every day I believe, but how often they're discussing my case I don't know. I don't know what's passed on.	My care needs is only maybe half an hour now, but she's great you know... She provides a <u>really</u> *emphasised* valuable service [carer].	I also feel that the kinda paperwork side of things, the bureaucracy, is getting in the way, is a lot of what we've been experiencing. It takes away from what should be at the centre, I think.
I'll never forget the journey home, coming up that road again, and I was in an ambulance and they drove me up... and just seeing the old road again... It was the most emotional kind of journey I've been on... I thought "oh my God I'd never see this again, kinda thing".	There was a number of multi-agency discussions that were happening throughout about me getting home.	We felt for my own good it would push me on, the less carers I had, to achieve more for myself.	The care that I got was as much about my mental health as it was my physical health.	My carer has had to do an awful lot off her own back in terms of managing this flexibility that is maybe required in my package now.
The consultant asked the nurse is it "district nurse treatable now?" and they said yes *eyes light up* and we kinda pushed for that, we were wanting to get closer to home, to have that as a kinda psychological boost as much as anything.	Being in the hospital for as long as I had, you build up relationships with nurses which is a good thing as well. So they were aware of the signs... ye know whether to leave me alone or whether to intervene.	We had four carers coming in at once, double ups as well when I was first out of hospital. But it kinda meant me coming and going back to bed and at that time I felt that the best thing for me was to stay up as much as I possibly could. I'm very much a kinda 'out-doorsy-type'	Person led, that should always be the priority. The person receiving care should be at the centre and to make it as non-complicated as it can possibly be rather than having all these agencies. It is bewildering at times	From my own personal experience there is still work to be done [re: integration of health and social care]*smiles* but I'm aware that there are good people trying to make it work the best they possibly can and it was always going to take time and kinda 'heal' and integrate.
The two physios that looked after me in [community hospital] were great and were very proactive with me. The facilities there, helped me get home.	I was on a feeding tube. There was all kind of internal issues that were goin' on at the time as well. But, you know there was always a reassurance there, you know that I was in good hands.	Throughout that period it was very person orientated. They looked after my mental health as well, as we were trying to do.	On the whole the care and attention we've received has been nothing less than exceptional.	My knowledge and my understanding and my acceptance, if you like, at what I'm going through is enhanced by the more people I speak to.
First referred to the service City Hospital	Initial assessment of care Community Hospital -> District Nursing Team	Planning of continued care Multi-Disciplinary Team (MDT) Meeting	Delivery of Care Neighbourhood Care Team	Present Day H&SCP
They give you everything they can, all the tools they possibly can, in order to make sure you're as independent as you can be ... but until you get to the home environment again and get out on your own... and you come across cracks in pavements?... You don't get that when you're in hospital, so you've got to learn all that.	And they were doing a lot of discussin' behind the scenes obviously, about what would be the best for my care. Whereas we were kind of 'Googling' things you know and looking for someone that was in a wheel chair that's had sepsis and trying to make out "oh there IS someone that's recovered from this" and we were getting little bits, of snippets of information.	There was nothing like that. These charities are <u>invaluable</u> *emphasised* but they're never ever mentioned and I don't understand why? We had to hunt far and wide for the right charity ourselves. There's no discussion there. You need a network.	I think that's the difference you see. If they have a phone call [District Nurses (DN)] then they would go out and deal with that away from you and they won't discuss other cases. That's a definite difference between the nursing staff and carers.	It's communication. I've had a number of experiences since I came home where we don't want to cross the visits between DNs and carers, and that comes from them talking to each other... but when you go to their head office they don't see faces... they don't see that harm that [wrong times] can cause to a care package or to the trust that you have in somebody turning up on time.
There is a fear of the outside once you've been in hospital for a long time, I 'get that' too.	My wife was getting very anxious that she couldn't find anyone specific to my own symptoms.	The level of care we get now is just right now. It has taken about a year to get that level.	In the past five months we have had four different carers. In a wee town like this? [We felt there was confidentiality issues]. In small places like this it's paramount.	Who's best to contact? I know from my point of view, my social worker is who I'd go to for the care side, but then is that being fed back to the NHS side? The Doctors, The Nurses, The Consultants?
It took them a bit of time to get everything together from [inner city hospital] to [community hospital].	Initially it was quite fraught to start with in terms of people not knowing just exactly what outcomes were. That seemed to go on for a long, long time. There was an awful lot that just seemed to be happening on the hoof and it just seemed so overwhelming at times.	When you ask a consultant "is there anyone else I can speak to here" [re: charities] , you know it's "the chaplain" !	There's potentially protective practices, you know, "you don't step on my toes for this and you don't step on my toes for that" and I think that possibly is to the detriment of the service overall.	Person centred should be exactly that, as in individually rather than this collective ideology of what should be done. I think it can be lacking sometimes around individual needs and individual focus.
	I was in a coma for 3 weeks and in the aftermath of all that there was an awful lot of uncertainty and we were asking questions of the consultants at that time, that the consultants obviously couldnae answer at that time... and at THAT time you're just wanting answers. It was difficult for EVERYBODY involved.	I don't know what's passed on there [re: current multidisciplinary meetings]	You tend to find that the carer comes in a week later and her head office is telling her something completely different, and I can't control that obviously.	
	When you asked them "when is such an' such gonna happen", "How long can I expect to be in here?" It's just a load of questions that just could not be answered. And at the time that was the biggest thing that frustrated us was nobody had the answers.	You tend to find that conversations are either slanted towards a healthcare or a social care need depending on who it's with, and there seems to be a disconnect.	I think communication-wise that's where the most frustration lies but in terms of the actual care and attention that I receive we can't say there's any complaints there you know from the NHS and the care sector.	
	There was a lot of debate about whether they [community hospital] could support me or not, and they were going to change my wheel chair, and I didn't want that. I was determined I was going to be independent again. They got me in an upright chair, but I was able then to whizz round *smiles* and show them that I had that capability and be mobile again.		There does seem to be a couple of extra steps and it seems like chinese whispers at times [communicating to head office] I felt that over a period of time too.	
			I've always been independent, especially with the wheelchair, so I probably wanted to push that away [full care package] cos it was my pride that was being hurt... if that makes sense>	

There are five principles of Neighbourhood Care in Scotland and these are:

- 🎯 Putting the person at the centre of integrated holistic care and own care promoting wellbeing and independence.
- 🔗 Building relationships with people to make informed decisions about their own care.
- ❤️ Enabling person-centred care at the point of delivery.
- 📍 Small self-organising, geographical-based teams.
- ☁️ Professional autonomy.

Discuss where the diamonds  are placed on the patient journey, on the other side of this paper.

- What principle does each diamond represent?
- What other examples do you have in working to these principles?
- How can we align our work more to these principles?

Notes:

Ideas for quick discussion points

They give you everything they can, all the tools they possibly can, in order to make sure you're as independent as you can be ... but until you get to the home environment again and get out on your own... and you come across cracks in pavements?... You don't get that when you're in hospital, so you've got to learn all that.

Q: How can we prepare and support people better before they are discharged?

Q: What organisations can facilitate this in your area?

And they were doing a lot of discussin' behind the scenes obviously, about what would be the best for my care. Whereas we were kind of 'Googling' things you know and looking for someone that was in a wheel chair that's had sepsis and trying to make out "oh there IS someone that's recovered from this" and we were getting little bits, of snippets of information.

Q: How can we communicate information better with people?

There was nothing like that. These charities are invaluable *emphasised* but they're never ever mentioned and I don't understand why? We had to hunt far and wide for the right charity ourselves. There's no discussion there. You need a network.

Q: How can we help build a better supportive 'informal network' for the people we care for?

I don't know what's passed on there [re: current multidisciplinary meetings]

Q: How can we ensure the conversations we have are person-centred?

You tend to find that conversations are either slanted towards a healthcare or a social care need depending on who it's with, and there seems to be a disconnect.

Q: How can involve people more in the conversations and decisions regarding their care?

Person led, that should always be the priority. The person receiving care should be at the centre and to make it as non-complicated as it can possibly be rather than having all these agencies. It is bewildering at times

Q: How can we better co-ordinate our conversations/communication with each other?

I think communication-wise that's where the most frustration lies but in terms of the actual care and attention that I receive we can't say there's any complaints there you know from the NHS and the care sector.

Q: What would make conversations better with the people receiving care?

Person-centred should be exactly that, as in individually rather than this collective ideology of what should be done. I think it can be lacking sometimes around individual needs and individual focus.

Q: What would help us deliver care that is more person centred?

Q: What would help us deliver care that is more holistic?