

A community nurse’s view of the care experience journey



Sarah and Shona are community nurses. They work in an HSCP that covers a very rural environment. Team members here have been focusing on improvement activity around palliative and end of life care.

Journey Service pathway

These comments and quotes from ‘discovery interviews’ with people delivering 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**

		I personally feel that our communication with the GP is far safer when you're co-located, cos if not you really have to rely on the GP phoning you back and you're chasing the GPs maybe all day..but you don't have the problem when you're working in the same building		There's this lady with a catheter, and we've had a lot of problems in the past month so we'd just put suggestions to the carers over the past few days e.g don't leave an overnight bag on all day, put a flip flo valve on it, you know.		It all happened very quickly. She was sent home as palliative, came to the local hospital. She wanted to die at home, was discharged the next day so we had to work very quickly to get things in order and I think we work great as a team									
		I think it's just that we're smaller, a small community [what is the secret to better integrated communication] and everybody knows everybody else.... we just all know each other.		We would talk together to see so we're not all arriving at the same time		We try our best to cover our own end of life care if it's our patients. We try our best to cover out of hours, so the patient knows the nurse... so you're not introducing a nurse from one of the other teams.		The decision is ours really, I think that probably is unique here. We have the autonomy to do that within the team.							
MacMillan contacted us and said look she's arrived here on Thursday and she's desperate to get home, can we get her home tomorrow?				I don't know if it's unique to just here that we work so closely together, I'm talking about before 'integration' we worked VERY very closely with social work and home care,		Sometimes they might be very private and they don't want anyone knowing, but you always ask the patient. If the patient wants it [family members involvement] that's what we do.		They're there every day sometimes four times a day so they're there picking up a lot of things that they then share with us.		We've got a really good relationship with community equipment, ye know, the boys that do the deliveries. They can be out the same day delivering a community bed and a pressure relieving mattress, chair, sani-care commodes..if they can.		Sometimes it's actually quite nice just to put closure on the whole thing with the nurse involved and it's nice for the family I think as well.		We would continue to support if we felt that they needed it.	
We speak daily with the hospital and we keep that link		We do work well together, we do communicate VERY well..		We do our own projections, we decide.		Our first point of contact would always be with the patient, we respect THEIR wishes.		They [carers] feedback what goes on, you know the dynamics of the household/areas of concern.. and it's good for us to know that.		It's home care that does all the personal care but if there's any issues with skin, and so on, they highlight that right away.		I don't think we've ever said to a patient "we can't sustain this and you HAVE to go into hospital"		We go back and do bereavement support, it's just something that you know, it comes with experience.	
We're quite often in the situation where we're based in the GP practice, so the GP, we have a meeting with him daily, 10mins every day. If there's anything he'll just pop into our office for a discussion about it.		Some people think 'well it's the nurses that should care manage or social work should care manage', you know. It kind of should be based on the need.		We work it out between ourselves [rotas] and we know though experience when it comes that you're going to be on call for that patient. We rotate the visits so the four of us are involved with the patient.		Sometimes we do the initial meeting jointly with MacMillan if there's a patient she's maybe been involved with and we're only coming into that episode of care at that stage.		The carers are at that weekly meeting with social work and home care.		There probably is [a specific referral form] but nine times out of ten we just pick up the phone and chat first, they might then ask us to fill out the electronic referral form [podiatry/physio/OT]		I went in to do, maybe a dressing change, but the patient had died just before I got there.. So then, you just carry out last offices.		We might pick up on something else and taking that person on, on the case load.	
We know the background, maybe, because of these meetings.		It's not always the number, it's the quality of the patients on your case load and the time you have to spend with them, you know, nearing the end of life. And their families.		It's just a phone call and the community equipment will be delivered very very quickly in these situations, you know, even over a weekend.		We introduce ourselves, maybe the two of us and what our role will be, how they can contact us.		It would be hospital care for that patient if we didn't have the flexibility within our team to cover these.		It gives a better episode of care for the patient if you're all communicating.		You build up a rapport obviously with the patient and family.. Professionally and naturally you want to be there for that person as much as you can, you know.		They've [Macmillan] got a great support network for after bereavement for families as well.	
Person requiring care is first referred to the nursing team		Assessment of care need		The planning of care		The first visit to the person's home		Arranging follow-up visits		When a person deteriorates/need specialist care		When the person dies		After this?	
Normally DNs meet weekly with GPs and Macmillan Nurse. In this scenario she was discharge to community hospital and MacMillan nurses contacted DN team		Initial assessment when admitted to case load, a combination of tools in patient held record doc... Assessment of daily living, Waterlow, moving and handling, falls etc. takes ~ 1.5hrs		Agreed by MDT at weekly meeting		Usually joint visit with MacMillan Nurse where ever possible.		Next visit is planned for and agreed with the patient at the end of the last visit		Dependant on the circumstance; the nurse relies on experience and professional acumen when referring to specialist services (usually by phone first of all)		Last offices carried out (sometimes with family members)		Bereavement counselling visits arranged. Team meet to reflect on care experience	
They're identified maybe weeks before we become involved.		I think there's sometimes a stigma attached to it, and cancer, and people knowing that if the MacMillan nurse is there, then that you've got cancer.		We could be doing 150miles a day, quite easily.		Sometimes, depending on the case, we might phone the day before and say 'look we're planning to come to see you tomorrow between 9 and 12' and we'd say to them then, if there's family, is it ok to speak in front of your family or do you want it to be done just you and us-kinda thing.		They [carers] have their own folder as well, but if there was any issues they'd report it to their line managers and then they [managers] would either phone or e-mail us.		When it goes on for a long period of time, well emotionally, you're drained.		We had a whole week of where we just did on call ourselves... day and night...so we were physically drained at the end.			
		If there's more nursing needed, the care managing would be left to the nurses to do...if it's more 'care' social work would take more of a lead there.		It's not my favourite part of my job, no. [providing OOH/24hr care].				We've got a lot of different weekly meetings!		We go 2nd on-call if one of our patients becomes end of life, but would have to put that past [someone]. We probably have to get that checked because the cost.					
		There probably is a wee bit of a difference, we see things that they don't and vice versa [single shared assessment]... like health and safety maybe.		The other problem we have is our IT systems don't talk to each other. So you do the assessment and bounce it back to social care. So there's a lot of duplication that way				The carers probably don't see the single point assessment but we do share with them, they're in there ever day so they need to know what the patient's needs are.							
		I think we find the single shared assessment more onerous, you know, they're just so... I mean how many pages are there? About a 20 page assessment, and that can be						It could be us MacMillan, OT and home care all visiting the same Pt, but what we try to do, we try to work our visits with MacMillan so if we are there on a Monday then MACMILLAN then visit on a Tuesday...							
		You need to have the infrastructure in place first [re: ipads replacing digipens]													

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.

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

Notes:

Ideas for quick discussion points

They're identified maybe weeks before we become involved.



Q: Is this a good thing?

Q: Could/Should our involvement be sooner?

If there's more nursing needed, the care managing would be left to the nurses to do...if it's more 'care' social work would take more of a lead there.



Q: Do you feel that personal care is part of the nursing role?

Q: Discuss what is meant by 'care' (such as social care, health care)

The other problem we have is our IT systems don't talk to each other. So you do the assessment and bounce it back to social care. So there's a lot of duplication that way.



Q: How can we minimise duplication of effort?

Sometimes, depending on the case, we might phone the day before and say 'look we're planning to come to see you tomorrow between 9 and 12' and we'd say to them then, if there's family, is it ok to speak in front of your family or do you want it to be done just you and us-kinda thing.



Q: Should/could this happen all the time?

Q: Can visiting times be better managed?

The carers probably don't see the single point assessment but we do share with them, they're in there ever day so they need to know what the patient's needs are.



Q: How can we improve the communication between home care and nursing staff?

When it goes on for a long period of time, well emotionally, you're drained



Q: How can we better care for ourselves?

Q: What support do we feel is needed?