

Appendix 2: Development of Consensus Statements from a Focus Group

Domain 1: Structures and Processes of Care

	Quality Statement	Rationale	Evidence Base from the Focus Group
1.1	Patients approaching the end of life receive care that is well coordinated across different settings, services and providers.	Care at the end of life for PD patients can occur across multiple different settings: both inpatient (admissions to the hospital or hospice), outpatient (clinics with specialists) and in the community (at home or in residential/nursing care facilities). For end of life care to be delivered effectively with continuity, there must be multidisciplinary and multi-agency collaboration. Local structures should be in place to facilitate integration of primary and secondary services.	<p>"I think it's wider than just end of life, actually. If the networks and joined up care was there earlier, then it would be easier and more joined up at the end of life as well." Participant 3</p> <p>"A lot of what seems to go wrong in terms of service delivery is the fact that primary care is in the dark, really, they don't have explicit instructions about how to deal with patients." Participant 8</p> <p>"One of the things that is absolutely fundamental about developing these services is establishing this trusting relationship between colleagues working in those different settings...giving each other confidence that we trust one another to look after our patients when they move between those settings as well." Participant 10</p> <p>"Your palliative care consultant or your geriatrician or your neurologist should be talking to each other about these folks so it shouldn't be left to a general medic to be doing it on their own, so we should be sharing experience for the individual patient and then sharing wider experience, that's the only way we are going to improve this." Participant 6</p>
1.2	A named keyworker is responsible for the organisation and integration of an individual's care.	A named keyworker can act as a centralised point of contact for the patient, their family and other healthcare professionals. A key worker can also act an advocate for the patient, ensuring that they access the care that they require.	<p>"We go back to where this all started in the Room for Improvement document, you can see that the ones that got the best experiences were the ones who had a Parkinson's disease nurse specialist...and I don't think we have really moved on from that evidence, and yet the systems are moving away from that evidence, which seems to be a bit odd to me" Participant 4</p> <p>"So I think it's becoming much more important [to have] the PD nurse on the end of the phone...may be much more important than anyone who works in the community" Participant 5</p>

			<p>"What you are talking about is this care coordinator role that is advocated in dementia as well. I think that's really important." Participant 6</p>
1.3	Digital healthcare records are available to facilitate data sharing so that a patient's prior expressed wishes and clinician input can inform future episodes of care	Digital health records that are accessible to different services within a local region enable sharing of patient specific information, thus ensuring that ACP documentation and end of life plans are easily accessible.	<p>"And the biggest challenge I've found – we never use the same system. Hospital uses a system, the community uses a system. I'm tired and exhausted about [getting a] platform to share those plans." Participant 1</p> <p>"Systems talking to each other is a real pain. I'm told, I don't know how true this is but NHS Scotland have a much joined up system using fewer platforms which talk to each other, which makes planning end of life care so much better." Participant 2</p>
1.4	Red flags are identified that trigger a referral from community care to specialist Parkinson's palliative care services.	It is important that acute deterioration is recognised in a timely manner. Such red flags could include the use of a rotigotine patch, or a patient's first aspiration event.	<p>"From my perspective, and if I'm putting someone on a patch...[I] contact the Parkinson's team to let them know it's commenced... and that starts our ball rolling and we know every other day...we're touching base, titrating, moving things round..." Participant 7</p> <p>"the fact that putting on a patch isn't the end of it, it's the beginning of it...I think that actually I would like a situation where someone considering a patch raises a red flag, and you are getting people involved...and that ideally we'd have PD palliative care services that could reach out into the community and support folks in the community so that...so instead of "what dose of patch should I use?" the question is "I'm worried this person is dying of or with their PD, please get involved!" Participant 6</p>
1.5	Health and social care workers have the required knowledge and necessary skills to provide high-quality care to patients approaching the end of life and their families and/or carers.	It is important the generalist and specialist services providing care for PD patients at the end of life have a multidisciplinary workforce suitably skilled to deliver excellent care. Education of the whole multidisciplinary team in both primary and secondary is a priority to strengthen and improve end of life care for Parkinson's disease.	[in response to perceived gaps in PD palliative care] "better education of the whole MDT in recognition of what end of life care is in PD, and even us here on this forum today will have different ways in which we identify people with end of life care in PD so I think better education would be great actually" Participant 1

Domain 2: Preparing for the end of life

	Quality Statement	Rationale	Evidence Base
2.1	Patients are encouraged to use advance care planning discussions to develop their priorities for care at the end of life with the flexibility for change.	Advance care planning is a process and not merely an outcome, with the focus on building up trust between the patient and the healthcare professional, and the sharing of mutual uncertainties and fears.	<p>"But actually for me the big things [of ACP] are building up of trust, shared care, things you cannot measure, quality of care, opportunities to share your fears...you cannot measure that stuff... And even if you don't have a document at the end of it, actually the whole process is so deeply, deeply powerful" Participant 4</p> <p>"It's, I always tell them, it's about creating an opportunity for your patients to talk about future...It's purely about creating a conversation" Participant 1</p> <p>"The other thing just to throw in would also be the uncertainty, that's another symptom. The whole uncertainty of prognostication, I think, people find really disabling, and I think doctors do. I think living with uncertainty is something we need to help ourselves to do, and others to do." Participant 4</p>
2.2	Advance care planning involves the patient, their family and <i>all</i> multidisciplinary team members.	Utilising all care providers, from family members to therapists and consultants, in ACP discussions ensures that the patient's holistic needs are considered. Conversations about dying and death be normalised, rather than medicalised.	<p>"Then I realised that I was doing that [ACP] badly, because every time they came to see me they always expected this chap to have a bad conversation about, gosh, where they were going to die... So what I decided to do was use the MDT. So every time they saw the other members of the MDT, either in the hospital or the community setting, they could touch base with them. The HCOP consultant can do it."</p> <p>Participant 1</p>
2.3	Planning for the end of life is started in a timely manner early in the disease trajectory according to patient needs and wishes.	As Parkinson's disease progresses, cognitive and communication issues may impair decision making. Thus, ACP discussions should be offered well before the patient enters the palliative phase.	<p>"And I think the problem with PD is the cognitive change, some of these discussions can't be left because if you don't do it this week, next week or next month you might not be able to do it at all." Participant 5</p> <p>"I think it's more of a reflective point, isn't it, in terms of rather than externalising it and asking when does the patient want me to have this conversation, it's saying, if I'm not having many of these conversations why is that? Am I open and receptive to it?" Participant 6</p>
2.4	Advance care plans are reviewed with patients and their family at regular intervals, where appropriate, to facilitate	The disease trajectory in Parkinson's disease is often unpredictable and fluctuating in nature. Patients should be offered opportunities to regularly review and develop	<p>"So actually, when we are having these discussions, or making judgements, what you find is that people can do that because they adapt... What people do is cut their cloth according to where they are in their trajectory. And one of the things we need to work on in all branches of medicine is to understand that process. We need to</p>

	changing expectations and goals of care.	their care plans in accordance with their changing needs and preferences.	<p>understand what helps people adapt, how we can facilitate adaption, how we can help people recalibrate their quality of life." Participant 4</p> <p>"I think trying to capture how you feel about this at 60 is going to be different to how you feel about it at 65. The things that you said were completely intolerable, or I could never live like that, actually...we know...you may not feel that way when it actually comes to it"</p> <p>Participant 6</p> <p>"And often I think if you hold the emergency healthcare plan as gospel when the situation changes, patients can end up in a situation which isn't ideal." Participant 9</p>
2.5	Patients have high quality contact with services, including time that is unrushed and continuity of expert care and information.	Time is a priority for patients with Parkinson's disease. Appointments and visits should allow sufficient time for thorough assessment and discussion of present and future needs.	<p>"It definitely is, with complex patients who come in face to face, it definitely is a benefit in having that extra time, that we have to have, because it's the rule now." Participant 12</p> <p>"My personal view is that patients want three things – they want time, they want continuity and they want expertise" Participant 4</p>

Domain 3: Care in the last weeks of life

	Quality Statement	Rationale	Evidence Base
3.1	Care at the end of life is holistic and individualised.	Care at the end of life is patient centred, taking into account the physical, psychological, cultural and spiritual dimensions of the patient.	"[on what would be the most important area of research] "I think the biggest difference would come from having the time to have an individualised prescription of care for every patient . Quite how we deliver it is another matter." Participant 2 "The biggest symptoms is...trying to get them to communicate with you, on not just the physical things that they are feeling, but the whole understanding of the situation and the meaning of self. I think that for me is a huge huge challenge that we may never get to the bottom of. Yeah, so that's what I think, in terms of assessing the essence of the person " Participant 4
3.2	Dopaminergic medication is delivered in the appropriate dose and form, with consideration of both patient symptoms and drug side effects. There is regular review of dopaminergic medication by experts in PD/palliative care.	Dopaminergic medication should generally be continued at the end of life. Nonetheless, dopaminergic medication may be less effective, cause side effects or be difficult to deliver via the oral route. Assessing a patient's response to dopaminergic therapy and the appropriateness of reducing dopaminergic medication should be done with the expertise of a movement disorder specialist or CNS.	"I think actually, trying to determine who is dopaminergically responsive, or how likely..it's not going to be a dichotomous thing, it's going to be a continuum...trying to determine how dopaminergically responsive they are versus how worried we are about side effects, will help us, and what routes are available for us " Participant 6 "People think that they've just stuck on a patch and they've done their job, but this idea of review, review, review... keeping a good close eye on the patients , seeing how the relatives are doing...are we giving them hallucinations, are they more drowsy with the medications..." Participant 4
3.3	Terminal symptoms are carefully assessed and diagnosed to guide appropriate management.	Patients with Parkinson's disease often have troublesome symptoms at the end of life, including pain, nausea and delirium. It is important that the root cause of the symptom is investigated to ensure that underlying issues, such as intercurrent infections or constipation, are identified.	"But, aside from that, the other bit at the end of life, I think is the deconstruction of symptoms. You see delirium and you give sedatives because someone is agitated... you need to deconstruct what's going on , you need to go back to the constipation, the pain, the rolling in bed, the catheter..." Participant 6 "I think there's some very basic things which often get missed . I've seen some patients that have been in absolute agony with constipation and just basic things like that have been overlooked." Participant 8
3.4	Management of symptoms follows guidance that is specific for patients with Parkinson's disease, e.g. the Palliative Care Formulary.	The PCF offers a comprehensive guide to management of rigidity, nausea and vomiting, pain and delirium.	"You very kindly put your formulary in the email, and we've got a formulary, but I know from investigations that I do, because I've got white hair and have been here forever, that people don't always follow them, and I wonder why that is." Participant 5

Domain 4: Care in the last days of life

	Statement	Rationale	Evidence Base
4.1	The dying process is often difficult to predict, and this is acknowledged between patient, their family or carer and the healthcare team.	Parkinson's disease lacks a predictable trajectory, and recognising the dying phase can be challenging. This prognostic uncertainty should be acknowledged by healthcare professionals and shared with the patient and their family.	"We are far better at identifying dying in the cancer setting...what the trajectory looks like...what symptom burden looks like. If I ask my palliative care colleagues to identify dying PD patients, I think they would struggle... because they don't tend to see that very often...." Participant 1 "there is something about having confidence in diagnosing dying and in being able to do that having ruled out dopamine responsiveness or lack of it..." Participant 10 "Secondly, is the duration of dying . Healthcare professionals start to struggle with that concept...particularly if you are in an acute hospital setting. If the dying process takes more than a few days, people start to question their decision making and leads to more interventions, leads to more treatment, mixed messages to the family" Participant 1
4.2	Patients who have signs and symptoms that suggest they may be in the last days of life are monitored by healthcare staff and/or family so that responsive and compassionate care can be provided.	It is important to utilise the family and all members of the multidisciplinary team to support patients in the terminal phase. Family members and nursing staff are particularly equipped to recognise signs of terminal agitation or distress.	"I think that ties in with work that was done by Hubbard...I think the way that she put it was that they are ' exquisitely aware ' of when patients are changing, and that context is vitally important." Participant 4 "Skilled staff are really important in terms of the nursing care... if you look at the data around those in hospital who are best at predicting who is going to die, it's the healthcare assistant ...and that's because they are doing most of the handling...and I suspect when you get to know a patient and you know how they handle and move, you can actually see where the issues are lying" Participant 4
4.3	Anticipatory medications are prescribed appropriately for Parkinson's patients.	Patients should be prescribed anticipatory medications with individualised indications, avoiding D2 antagonists that may precipitate extra-pyramidal symptoms.	"The [EOL] drugs we want to avoid are...naturally there, which means that these drugs need to be deleted [on prescribing systems] for people with Parkinson's. And you can see that it's all with good intention but as soon as they give a haloperidol dose, all that good intention is completely, completely lost " Participant 3
4.4	Comfort, rather than location of death, is a marker of quality end of life care.	A 'good death' does not necessarily mean death outside of hospital. Regardless of location, maximum comfort and time with loved ones should be markers of a 'good death'.	"If you talking to people about what is a good death, then generally, although there is this notional thing about being at home, actually you want comfort, you want your family around you and... the place where you die is the least of it, really " Participant 4 "Sadly CQC are very focussed on preferred place to die. It's such a pain because preferred place to die is not a good measure of good death , and I can't stress that enough, either in the cancer or non-cancer setting" Participant 1

4.5	Bereavement support is available for families and carers, both immediately and in the long-term.	Families and carers should be prioritised after the death of a loved one, and should be offered emotional, spiritual, social and financial support.	"[Bereavement] is something that palliative care in terms of cancer does very well but we don't really pick up on bereavement in most Parkinson's services and support for relatives afterward." Participant 10
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