Inquiry into Access to Palliative Care Services

Briefing to NI Assembly Committee for Health

RCGP Northern Ireland is the membership body for general practitioners in Northern Ireland; we promote and maintain the highest standards of patient care.

As a college, we recognise the growing importance of palliative and end of life care in current and future health service provision. RCGP has an important role in working with partner organisations to advocate for provision of universal access to generalist palliative care for all those affected by life limiting illness, and for equitable access to well-targeted specialist palliative care.

GP role in provision of palliative care

GPs play a vital role in providing palliative care. Embedded in the local communities that we serve, we have a deep understanding the specific health needs of our local population, and the majority of palliative and End of Life Care (EOL) services for patients is provided by generalists (GPs and District Nursing teams).

Providing care from cradle to the grave, we understand the privileged role we have in caring for our patients and their families to support living well when curative treatments are no longer appropriate. Importantly, we support our patients to have a good death. It is vital to stress that palliative care encompasses not only end of life care but also helps patients and their families to 'live better' with non-curable conditions, which can be cancer and non-cancer related. GPs are often the first to identify palliative needs and will initiate and intensify symptom management, referring to specialist services if required. We assist with end-of life planning, we coordinate care and are often the central link in the multi-disciplinary team. Vitally we provide continuity and support to patients and their families, who are often also our patients, and our support to them goes on after their loved one has passed.

As patterns of illness change, due to advances in medical treatments and technology, the role of the GP in palliative and end of life care is ever more challenging. Multimorbidity and complexity are rising, and more people, of all ages and with a wide range of conditions, can be considered to have palliative care needs. These can be physical, psychological, social and spiritual . Prolonged functional decline results in difficulties identifying the end of life, particularly for those with non-malignant conditions. GPs are more likely to be able to identify patients in the last years of their life, rather than the last year.

Workforce and Workload

Current challenges in our health system at large, but more specifically in the arena of general practice are impacting on our ability to provide services to all our patients, including patients in need of palliative care.

Long term underfunding and inadequate workforce planning has led to well documented challenges in general practice. As a result, we have a workforce dealing with high levels of moral injury and burnout, a crippling wave of contract hand-backs and crises in recruitment and retention, which all lead to an unsustainable deficit between demand and capacity. Self-reported data collected by the Northern Ireland Medical and Dental Training Agency (NIMDTA) through the GP appraisal process indicates that the number of whole time equivalent (WTE) GPs has fallen by around 10 per cent over the past 10 years[1]. The ongoing 'shift left' strategy without commensurate funding, coupled with the effects of an ageing population on our system is simultaneously increasing our workload, leading to a perfect storm.

The issue of access to GP services has gained significant public profile following the COVID-19 pandemic, however primary care services had been under sustained pressure for many years prior. Indeed, as the NIAO March 2024 report highlighted, patient access challenges are a symptom of the mismatch between the increasing demand for and diminishing supply of services in general practice[2]. It is important to note that despite a contracted WTE workforce and real terms cuts to funding, the number of consultations has increased. Currently more around 200,000 consultations take place in general practice every week across Northern Ireland. Considered daily, that is 40,000 and it represents almost half of our population receiving a consultation every month.

It is without question that these issues are hampering the ability of practices to provide the high-quality care that patients need, and that GPs want to deliver. With respect to patients with palliative care needs, pressures mean that GPs may not be able to respond as quickly as they would aspire to, may not be able to see or visit their palliative care patients as often as occurred in the past, and while we do our best to prioritise and respond to the needs of palliative care patients in a timely fashion, this will be to the detriment of other patients who also need our assistance as our capabilities are finite.

District Nursing teams work tirelessly, hand in hand with GPs to provide the best quality generalist palliative care that they can, but they too are hampered by excessive

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[1]NI Audit Office Report: Access to General Practice in Northern Ireland, March 2024: https://www.niauditoffice.gov.uk/files/niauditoffice/documents/2024-03/NI%20Audit%20Office%20Report%20-%20Access%20to%20General%20Practice%20in%20Northern%20Ireland.pdf

[2] https://www.niauditoffice.gov.uk/files/niauditoffice/documents/2024-03/NI%20Audit%20Office%20Media%20Release%20-%20Access%20to%20General%20Practice%20in%20NI_1.pdf

workloads, as well as challenges in recruitment and retention. A workforce that matches capacity to need in a more timely and responsive fashion would deliver better care and reduce the potential for delay in response time to urgent need e.g. administration of end-of-life medication.

It is noteworthy that across Northern Ireland, patients with palliative care needs do not all have access to a 24/7 district nursing service. In some areas while twilight and overnight services exist without normal district nursing teams, large geographical areas may need to be covered by single practitioners with the potential to negatively impact on a patient's symptom control in their last days of life.

For GPs to be able to deliver high quality palliative care input, the workforce and workload crisis must be addressed. Urgent action must be taken to stabilise practices and to make general practice in Northern Ireland a more attractive career path for the next generation, and for an increasingly diverse workforce. Any moves to improve access to palliative care services, must account for the current GP workforce and workload crisis and how this adversely impacts a GP's ability to effectively treat a dying patient.

Challenges across the region

There is a wide variation in the availability of palliative care services throughout NI. There are major differences in the provision of district nursing services, community services, hospital and hospice care. It can be very challenging as a GP, to help a patient navigate through the journey. Many practices span trust boundary lines, and the variation in services for patients living close to, but on different sides of an arbitrary line can create real challenges. It is not uncommon that two patients registered with one GP practice but living in different trust areas can have significantly different palliative care journeys.

In some areas, two community palliative care services exist, some of the roles of the services are overlapping, some are unique to each service, but healthcare providers can be left unsure to which organisation and service they should refer. Complex and heterogenous referral pathways compound the difficulties. These challenges create the real possibility that patients miss out on potentially life changing services, due to poor integration and lack of standardisation throughout the region.

The inverse care law, the idea that people who need medical care the most are least likely to get it, is highly applicable to palliative care access in the region. The patients who live in the most socio-economically deprived areas are affected to a greater extent than more affluent areas, with higher levels of early mortality, as well as having less access to community services, and fewer GPs per head of population.

Each patient in NI should have access to the same services, and there should be a large degree of homogeneity across the province, to ensure equity of access and to allow healthcare providers to refer to the appropriate service easily via easily accessible

regional pathways. We need pathways to deliver equitable services to all, but with enough flexibility to respond to the needs of specific communities (for example rural communities).

Points of access to unscheduled secondary care also vary across the region. While some areas have access to ambulatory and urgent clinics, as well as direct admissions (all of which avoid ED attendance for this vulnerable population), in other areas GPs have no choice but to send palliative care patients to ED for specialist assessment, knowing that they will wait inordinate amounts of time for assessment, and admission if required.

Medicines and Prescribing

For patients at home or in residential and care home settings, GPs are largely responsible for palliative and EOL prescribing. Palliative prescribing will invariably involve schedule 2 and 3 medicines and given the complexity and risk involved, these are not prescriptions that can be written and produced in a multitasking environment. There is a huge onus on GPs to carve out protected time to reduce error / manage risk and get it right for the patient in a time critical manner.

Given the multidisciplinary nature of both community and specialist palliative care provision, it is vital that communication between specialist provider and generalist teams are good. GPs try to prioritise prescribing in the palliative and EOL scenario and with workload constraints this will invariably add to an already overburdened day.

In the generalist setting the communication between the District Nurse and /or Palliative Community Specialist Nurse is a key one, working together to support patients. It is important however to note that the prescribing and therefore the medicolegal risk almost always rests with the GP as the number of non-medical prescribers in this area are few. In any setting it is important that the prescriber satisfies themself that the prescription they are signing is appropriate and safe and as such effective and timely communication between the GP and other members of the MDT who are non-prescribers but making recommendations regarding medicines allow for this to happen in a way that supports safe, effective and timely care for the patient.

There are often instances when supply issues create problems for EOL prescribing and medicines availability / stock can mean that alternative medication is required which potentially can impact upon symptom control. Families can spend time collecting prescriptions from their GP practice and often travelling between pharmacies to find a supply of a medication, rather than spending precious time with their loved one. The fact that electronic prescribing is not available in Northern Ireland and will not be for many years, compounds these issues.

In the out of hours period district nursing teams will liaise with OOH providers to support a patient' palliative symptom control and EOL care. There are mechanisms for

GP practices in place to alert their local OOH provider of patients with complex needs or approaching end of life. As previously noted, availability of nursing teams to support patients in the out of hours period is variable and in some areas in Northern Ireland local communities are having to rely on charities such "Life and Time" to deliver timely treatment and support to patients at the end of their life.

IT infrastructure

There is insufficient integration of information regarding a patient's palliative and EOL journey across all systems.

GP practices have been computerised for many years and have highly advance clinical systems. Northern Ireland's hospitals and trust based services have now all migrated to the new digital system, Encompass. GP clinical systems do not currently interface with Encompass, and GPs have "read only" access to Encompass. This means that GPs must access a completely different system to gather important clinical information from secondary care, and it is our understanding that hospices and voluntary services have similar read only access to Encompass (if at all).

The rapid and safe transfer of data between organisations is hampered significantly by this lack of integration.

GPs have the capacity to upload a Key Information Summary (KIS) onto the Northern Ireland Electronic Care Record (NIECR) with information that is visible to hospital teams and to NIAS however as ENCOMPASS is rolled out and aspects of NIECR retired, a further gap will exist in how important information held by GPs can be made available colleagues working across the HSC in delivering palliative care

Currently referral by GPs into palliative care services is via yet another IT system (CCG). Different pathways exist for community and specialist palliative care which in some areas, also includes referral to hospice units for admission. A GP working across Trust boundaries needs to be aware of the potential differences in pathways available to patients depending on their postcode. A project to co-ordinate services in the Belfast trust area, with a single point of referral to community palliative care services has recently been launched, and while it is still in its infancy, it has been welcomed by GPs.

After referral, most hospice services do not have capacity to write a clinical note on Encompass with GPs receiving electronic transfer of information from hospitals and from specialist palliative care services that is then uploaded to the GP record but not necessarily available to other members of the team looking after the patient.

While there are mechanisms for GPs to contact and communicate with OOH providers to alert them to palliative care patients who may need further support e.g. over a bank holiday weekend, these vary across trusts and other OOH providers

GP education and training

Education and training in palliative and EOL care is a key component of the GP curriculum and through workplace-based learning and examination to achieve MRCGP, GP registrars develop skills in the delivery of generalist palliative care.

Post qualification GPs are supported through further professional development resources such as the RCGP End of life and palliative care toolkit

In NI the Regional Palliative Medicine Group 2018 guidance document (2018) Management of Symptoms in Adults in the Last Days of Life, serves as a practical and helpful resource for GPs and palliative care teams.

Advance Care Planning

On 19 October 2022, Professor Sir Michael McBride launched the "Advanced Care Planning: For Now and For the Future" policy document for all adults in Northern Ireland

The Advance Care Planning Programme Team engaged widely during the development of the Advance Care Planning policy document and in addition to the document developed an Implementation Plan to support the policy document focusing on four implementation pillars:
Public messaging
Operational frameworks
Training and education
Evaluations and outcomes

The clinical component of advance care planning includes but is not confined to:
Declining health and unexpected emergencies
Best Interest Decisions
Recommend Summary Plan for Emergency Care and Treatment (ReSPECT)
Clinical Recommendations for Cardiopulmonary Resuscitation (CPR)

ReSPECT creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices. These recommendations are created through conversations between a person, their families, and their health and care professionals to understand what matters to them and what is realistic in terms of their care and treatment. Many areas in England and Scotland use the process and forms regularly, ensuring that patients can feel reassured that all professionals involved in their care are aware of their clear wishes.

Currently when patients become very frail, and approaching the end of their life, professionals will carefully consider the actions which should occur if that patient should suffer a cardiac or respiratory arrest. If possible, this is discussed with the patient themselves and family as appropriate. On many occasions, it is felt that performing

Cardio-Pulmonary Resuscitation (CPR) would be inappropriate due to severity of underlying illness or frailty. In this case it is decided that natural death should be allowed, rather than artificially attempt to restart breathing or the heart. This directive is often called a Do Not Attempt CPR (DNACPR) order. DNACPRs can be decided in hospital or in the community, however if a patient moves from hospital to community or vice versa, the DNACPR decision does not transfer and must be discussed again. This leads to duplication and potential distress for patients and their loved ones, having to discuss very sensitive and emotive matters repeatedly.

RCGPNI was involved at stakeholder level in the development of Advance Care Planning: For Now and For the Future policy and supported its launch but more than two years on are disappointed that work has not been progressed to implement this policy. We feel that it is vital that this work is taken forward as a priority.

Conclusion

GPs remain central to the coordination and delivery of high-quality, patient-centred care at the end of life. Our unique, longitudinal relationships with patients and families enable us to take a holistic view, supporting medical, psychological, and social needs. We are often the consistent presence across a patient's journey, helping to ensure continuity of care and advocating for patient wishes.

While highlighting the immense efforts of GPs and the wider multidisciplinary teams in trying to provide the best standard of palliative and end of life care for patients, we know there are a great many challenges that impact on our collective ability to do so. Recognising these challenges, we call for the development of a Palliative Care Strategy for Northern Ireland to address and support a gold standard service for all our citizens when they need palliative and end of life care.