

Review of access to palliative care services - Lived experience

Overview

The Assembly's Health Committee is holding an inquiry into access to palliative care services in Northern Ireland.

The Committee is keen to hear from patients and their families on their experience of accessing palliative care services in Northern Ireland.

Why your views matter

In this short survey we will seek your views on accessing services in order to identify gaps in services and areas where services can be improved. The Committee will make recommendations that will seek to ensure sustainable funding and high-quality care for patients with life-limiting illnesses.

What is palliative care?

Palliative care is an approach aimed at improving the quality of life for patients, both adults and children, as well as their families who are dealing with life-threatening illnesses. It works to prevent and relieve suffering through the early identification, proper assessment, and treatment of pain and other issues, whether physical, emotional, psychosocial, or spiritual.

Palliative care goes beyond managing physical symptoms; palliative care takes a holistic, team-based approach to support both patients and their caregivers. This includes addressing practical concerns and offering bereavement counselling. It provides a support system to help patients live as fully and actively as possible until the end of life.

Palliative care is recognized as part of the human right to health and should be delivered through person-centred, integrated health services that respect the unique needs and preferences of each individual at the time(s) when such care and support is needed.

What may palliative care be required for?

Palliative care is needed for a wide variety of conditions. Most adults who require palliative care have chronic illnesses such as cardiovascular diseases (38.5%), cancer (34%) and chronic respiratory diseases (10.3%). However, many other conditions also call for palliative care, including kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disorders, dementia, congenital anomalies, severe mental illness, and drug-resistant tuberculosis.

Who provides Palliative care?

Palliative care is delivered by a whole healthcare team using a multidisciplinary approach to plan and provide care that is tailored to the unique needs of the individual and their family. This team may include General Practitioners (GPs), Public Health Nurses (PHNs), Registered General Nurses (RGNs), carers, hospital-based healthcare professionals, pharmacists, counsellors, and other allied health professionals.

Specialist Palliative Care teams become involved when more complex symptom management is needed. These teams can operate in hospitals or the community, with many community teams based in local hospices. Hospices often offer additional services such as symptom control admissions, outpatient care, and day-care services.

The level of palliative care varies depending on the stage of the illness, with more specialised care provided by specialist teams as the illness progresses.

Palliative care can be accessed in hospitals, in residential centres, nursing homes, hospices and people's homes.

Consent

1 The Committee for Health would like your permission to publish your response as part of the survey results. Please indicate your preference

Consent *(Required)*

Please select only one item

- Publish response.
- Don't publish response.
- Publish my response but keep it anonymous.

Introduction

2 What is your name?

Name

3 What is your email address?

Email

Your experience of palliative care

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4 Are you an individual with direct experience of palliative care?

Please select only one item

- Yes
- No

5 Are you :

Please select only one item

- (a) a patient receiving palliative care
- (b) a family member or carer of someone receiving palliative care or who received palliative care
- (c) another person connected to a patient or family

Information on Palliative Care Services

6 Did you receive sufficient information on what palliative care is?
Please provide further information in the box below

Please select only one item

Yes

No

1000 characters

7 What services and support were you told was available?

1000 characters

Access to care

8 Where do you access the care services you receive?

Please select only one item

- GP
- Hospital
- Hospice
- Home
- Charity or organisation
- other - please give detail in the box below

1000 Characters

9 Where do you access the majority of your services?

Please select only one item

- GP
- Hospital
- Hospice
- Home
- Charity or organisation
- other - please give detail in the box below

1000 characters

Ease of access

10 How easy was it to access these services?

Very easy

Easy

Neither difficult nor
easy

Difficult

Very difficult

Please choose an option
Please select only one item

11 What made it difficult or easy to access services?

1000 Characters

Unavailable services

12 Are you aware of services which you/family/carer/friend were unable to access? If yes, please give details of which services and why were you unable to access them in the box provided.

Please select only one item

Yes

No

1000 characters

Additional Support

13 What additional support would be helpful to patients and families?

1000 Characters

Any other comments?

14 Do you have any other comments?

1000 Characters