AIIHPC

All Ireland Institute of
Hospice and Palliative Care

Report on Consultation to inform the redesign and redevelopment of The Palliative Hub – Carers

Contents

Introduction

The Palliative Hub – Carers was originally designed and launched in 2016 after a need for an online portal website on caring for a person with palliative needs was recognised by the All Ireland Institute of Hospice and Palliative Care (AIIHPC) and key stakeholders.

The redesign and redevelopment began in August 2025, following the launch of the National Adult Palliative Care Policy in September 2024. This work supports Strategic Action 3: *'Support the development of evidence-based training and support programmes for family caregivers supporting people with different care needs.'* It specifically addresses the activity (3.1) to "*Conduct a review of the Palliative Care Hub; use findings to inform its future development and the development of evidence-based training and support programmes for family caregivers"*

To support the redesign of The Palliative Hub – Carers, feedback was gathered from key groups including health and social care professionals and members of the public. There were one 2-hour online focus group with 12 Health and Social Care Professionals from across a range of disciplines which occurred on Tuesday 26 August 2025 and there was also a focus group with 8 Voices4Care members which took place on Thursday 28 August 2025. Voices4Care is AIIHPC's volunteer group that was established in 2013 to inform and influence the work of AIIHPC, its member organisations and the wider palliative care sector across the island of Ireland. Additionally, a survey was developed to gather feedback from a broader range of people which was circulated widely via the AIIHPC newsletter, AIIHPC's Social Media Channels (X, Facebook and LinkedIn), and via email to AIIHPC's wider network and Voices4Care members. The survey was live from the 15 August 2025 – 30 September 2025, and it was completed by 13 respondents. The focus group and survey questions can be found in the appendices of this document: Appendix A Health and Social Care Professionals Focus Group and Voices4Care Focus Group, Appendix B Survey.

The purpose of the consultation was to develop a better understanding of how users experience the current website and identify ways to improve its content, structure, and overall usability. Input from all groups was analysed to highlight common challenges and practical suggestions. This report summarises the main themes from the feedback and outlines clear areas for improvement for the new version of the site.

The site will be updated on an ongoing basis as and when new information or resources are available. The feedback mentioned in this document that has not already been implemented will be added to the medium- and longer-term planning of the site where relevant.

You can view the latest updated of the website on the "Latest News" section of The Palliative Hub – Carers by clicking here: https://carerspalliativehub.com/

Health and Social Care Professional Feedback

The 2-hour Health and Social Care Professional (HSCPs) Focus Group took place on 26 August 2025 via online video call. An invitation was circulated to a wide range of Specialist Palliative Care Professionals. 12 HSCPs attended across both Focus Groups including nurses, chaplains, quality officers, and other Allied Health Professionals (AHPs). Summary of the feedback is listed below and the questions asked are included in Appendix A.

1. End-of-Life Information and Support

Health and Social Care Professionals identified key gaps in what families know about the end-of-life stage.

- **Clarifying What to Expect** – Families often feel unprepared for what happens as death approaches. The site should include simple, reassuring information on physical changes, and common symptoms.
- **Eating, Drinking and Swallowing** – There is confusion around nutrition at end of life. The site should provide clear guidance on when food and fluids may no longer be beneficial, including how to respond to concerns about swallowing.
- **Emergency Preparedness** – Families need guidance on palliative emergencies, oxygen management, and who to contact in a crisis.

2. Inclusive and Age-Appropriate Family Support

Professionals flagged the need to better support all members of a family, including children and teens.

- **Resources for All Ages** – Signpost to bereavement support tailored for children and teenagers (e.g. the Irish Children's Bereavement Network).
- **Books and Stories** – Age-appropriate materials and book recommendations can help support communication with younger family members.
- **Initial Diagnosis Support** – More clarity is needed about what emotional and practical supports are available at the point of diagnosis.
- **Podcasts and other media** – Podcasts as well as other media should be added to the site to view information in different formats.

3. Access to Equipment and Medications

Feedback highlighted the importance of clear, practical information about physical care.

- **Essential Supplies** – Include information on common needs like catheter care, non-foaming toothpaste, and symptom control tools.
- **Videos on Equipment Use** – Short visual guides on using common tools (e.g. oxygen, mobility aids, hoists) would improve carer confidence.
- **OT Referrals and Home Adaptations** – Signpost to occupational therapy and explain how families can access practical support for home adaptations.

4. Promoting Carer Wellbeing

The group stressed the importance of carers looking after their own physical and emotional health.

- **Self-Care Messaging –** The site should reinforce that taking breaks is not selfish, but essential.
- **Support for Carers –** Include carer-specific organisations (e.g. Family Carers Ireland), with links to respite options, peer support groups and services.
- **Mental Health Acknowledgement –** Carers need validation for the emotional toll of caregiving and tips on recognising burnout and stress.

5. Improving Communication and Site Access

Communication and accessibility were repeated concerns.

- **Simplifying Language and Layout –** Ensure the content is accessible and written for the general public, not healthcare professionals.
- **Mobile Responsiveness –** Improve image display and mobile readability.
- **QR Codes and Quick Access –** Use QR codes to signpost to key areas or print materials.
- **'What's Available in My Area' –** Families may not know what exists locally. Regional breakdowns of services would help improve access.

6. Usability, Visibility and Digital Inclusion

Several participants noted challenges in finding or using the existing website.

- **Website Simplicity –** Content must be structured clearly and work well across all devices.
- **Bridging the Tech Gap –** Some carers may struggle with digital tools. Ensure the site is as accessible as possible.
- **Awareness Gaps –** Improve visibility of the website and its services

7. Community and Peer Support Integration

There is a desire for more community-based and peer-led resources.

- **Support Group Listings –** Include more regional or illness-specific groups (e.g. Alzheimer's Society, local hospices).
- **Local Events and Activities –** Highlight relevant events or carer drop-ins in different counties where possible.
- **Collaboration with Voices4Care –** Consider email outreach to gather local group suggestions and experiences.

Voices4Care Volunteer Group Feedback

The invitation to take part in this Focus Group was sent to all 61 members of AIIHPC's Voices4Care volunteer group of service users, carers and formers carers and people with an interest in palliative care. The 1.5 hour Focus Group took place on the 28 August 2025 online via Zoom, with 8 members in attendance. Summary of feedback from the discussions is listed below. The questions asked in this session can be found in Appendix A.

1. Travel, Holidays and Insurance

- Provide a list of available holiday homes or supported accommodation options for carers and patients.
- Include information on holiday insurance options for people with life-limiting conditions.
- Consider resources or directories for accessible travel, including drivers or transport assistance.

2. Financial Support and Home Adaptations

- Address the financial implications of caring, including access to grants and support for home adaptations.
- Signpost to reliable advice sources such as Citizens Information (ROI) and Advice NI (NI).

3. Multimedia and Mindfulness

- Expand use of podcasts, videos, and other media to make content more engaging.
- Link to mindfulness and wellbeing resources such as Headspace or YouTube breathing exercises.

4. Practical Information and Support Services

- Provide easily accessible, area-specific practical information including:
  - Local supports and services
  - Home care and night nursing
  - Advance care planning (Think Ahead in ROI, equivalent in NI)
  - Discharge planning and anticipatory care
  - Medication management, including nurse prescribing and anticipatory medicines
  - What to expect when dying at home, in hospice, or in hospital

5. Communication and Coordination

- Help carers understand:
  - Who may be coming into the home to provide care
  - Who the key contacts are in the care team
  - How and when to share information (e.g. with pharmacists)
- Suggest tools such as printed "key contact" cards for families.

6. Site Interactivity and Feedback

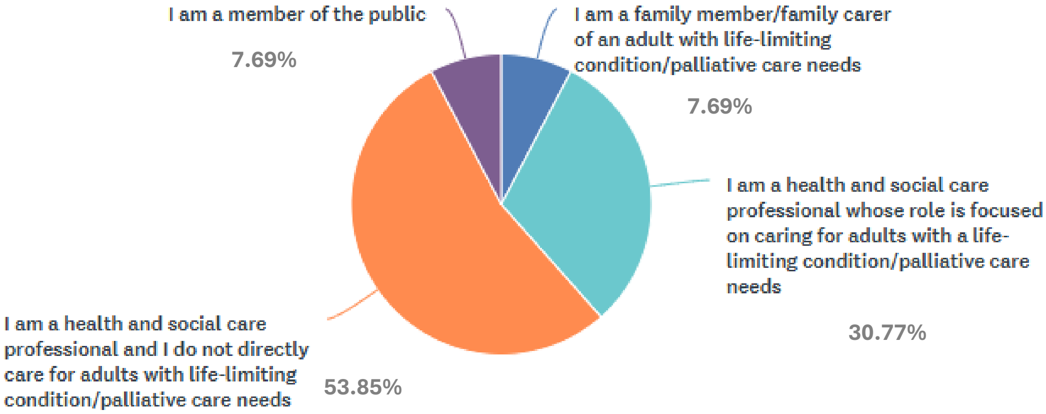
- Include a space for carers to leave comments or feedback on the care they've received.
- Continue updating core content (e.g. nausea and fatigue), and expand service listings and 'services' section

Wider Survey Results and Feedback

The wider survey was circulated widely via the AIIHPC newsletter, AIIHPC's Social Media Channels (X, Facebook and LinkedIn), and an email to AIIHPC's Voices4Care volunteer group and practitioner networks. The survey was live from 15 August 2025 – 30 September 2025. 13 respondents in total took part in the survey. Appendix C contains details the survey. See below a summary of the responses received:

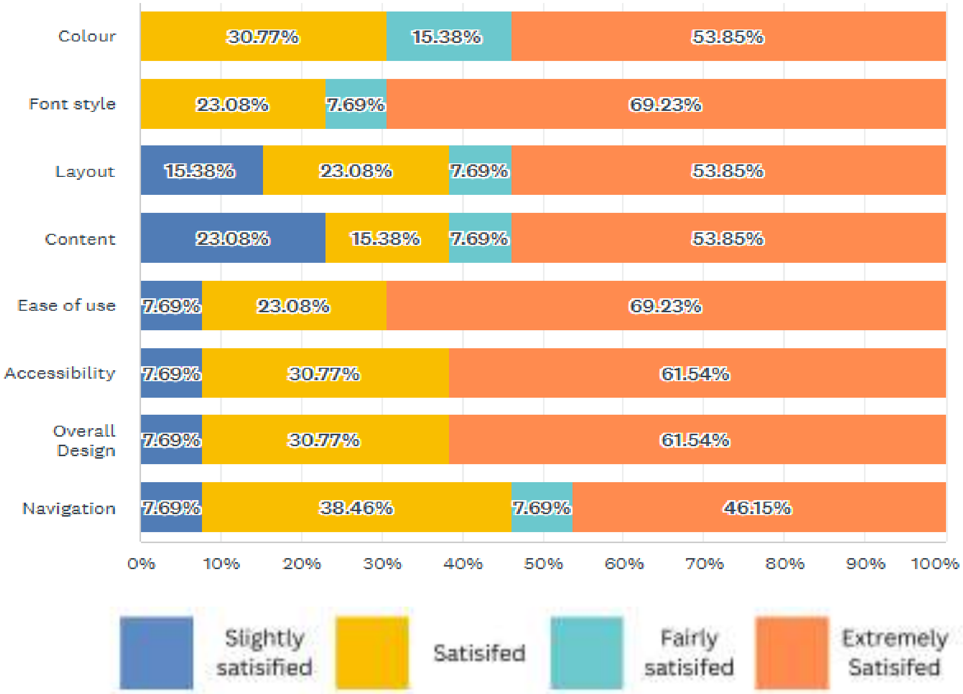
1. Respondent Demographics – "Out of the following, select the most appropriate for you"

The survey received 13 responses, with the following roles represented:



2. Website Satisfaction Ratings – "Overall, how satisfied are you with your experience of the following on the website"

Respondents rated several aspects of the existing website on a scale of 1 (not at all satisfied) to 5 (extremely satisfied):



Although satisfaction was generally high, layout, content and navigation received slightly lower scores, indicating areas for potential improvement.

3. Communication of Carer Support Services – "Do you feel that the website effectively communicates information and services available to carers? On a scale of 1 to 5, with 1 being not at all satisfied, and 5 being extremely satisfied"

Respondents were asked how well the website communicates information and services for carers.

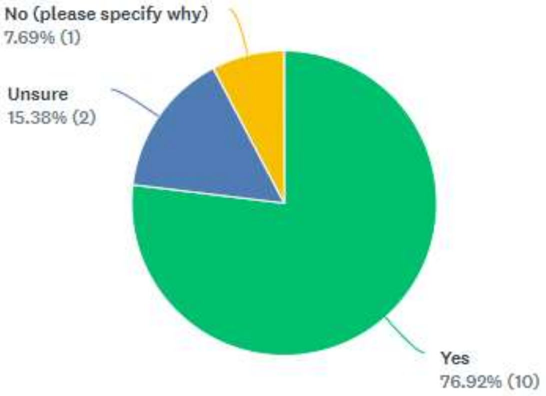
- The average rating was 3.62 out of 5
- 38.46% were "fairly satisfied," while 23.08% were "extremely satisfied"
- 23.08% were only "slightly satisfied," indicating room for improved clarity and visibility of services

4. Areas for Improvement & Requested Features – "What would you like to see added or changed on the website to make it more useful for you e.g. features or information"

Open responses highlighted several recurring themes:

- Add more real-life stories and practical advice
- Improve signposting to relevant local supports and services
- More information on advanced care planning, anticipatory medicine, and night nursing
- Resources on home adaptations and financial implications
- Include discharge planning guidance and explain who might visit the home
- Better communication aids and awareness for patients and carers
- Expand bereavement and symptom management content
- Add media content, e.g., podcasts and mindfulness exercises
- Improve regional relevance, particularly across different counties

5. Recommendation Likelihood – "Would you recommend this website to someone seeking information about caring for someone with palliative care needs/a life-limiting condition?"

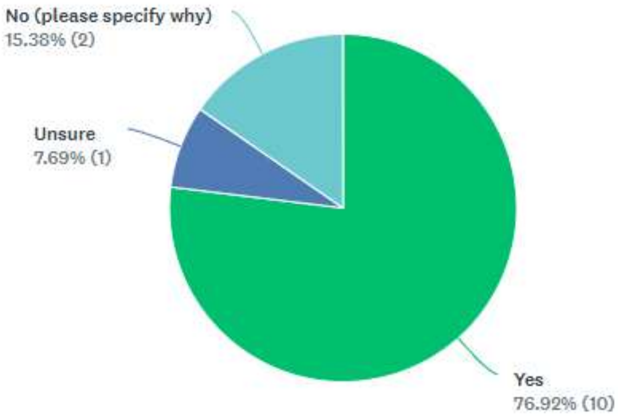


6. Helpful Website Areas – “Are there any specific areas of the website that you found particularly helpful or informative?”

Respondents identified sections they found especially helpful, such as:

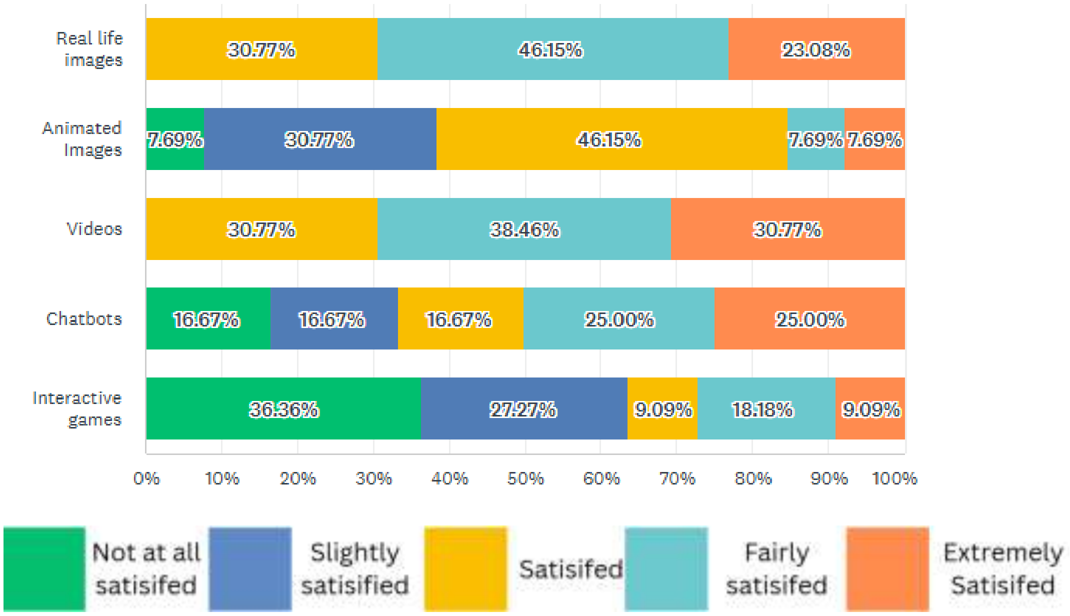
- Content related to practical care advice
- Emotional support and caring for the carer
- Clear layout and non-jargon language
- Specific resource links and service directories

7. Language & Tone – “Do you think the language and tone used on the website is appropriate and inclusive for the target audience (carers of adults with palliative care needs)?”



8. Content Format Preferences – “Please rate the importance of the following?”

Respondents rated media and content features by importance:



This suggests users favor engaging yet practical content, while gamification features are less valued for this audience.

9. Additional Comments

Suggestions included:

- Add feedback features for carers to reflect on their care experiences
- Cards or printouts for key contact information
- Information tailored to regional services (NI vs ROI)
- Improve clarity around roles, e.g., who may be coming into the home
- Simplify navigation and reduce information overload
- Add more accessible multimedia content and Headspace-style mindfulness tools

Conclusion

The feedback gathered through focus groups with AIIHPC's Voices4Care volunteer group, Health and Social Care Professionals, and the wider survey has provided valuable insight into the needs and expectations of carers across the island of Ireland in relation to informing the redevelopment of the Palliative Hub – Carers site. These consultations highlighted the importance of practical, accessible and relevant information for those caring for someone with palliative care needs.

Participants overwhelmingly welcomed a website focused solely on carers and emphasised the importance of user-friendly language, real-life stories, and tailored signposting to local supports and services. Both the survey and focus groups identified similar themes, including the need for improved navigation, enhanced emotional and mental health support, clearer explanations of available services, and more engaging content formats such as videos and audio resources.

Carers and professionals both emphasised the need for compassion in tone and balancing factual guidance with emotional understanding. Suggestions such as region-specific service listings, and improved information on advance care planning, home care, and end-of-life options highlight a strong desire for resources that meet carers wherever they are in their journey.

The development of The Palliative Hub – Carers has been informed directly by the target audience of the website, and the redesigned site aims to respond to their feedback by providing a compassionate, informative and easy-to-navigate site.

Based on the feedback across different methods, various improvements have been made including:

1. **Improved accessibility and easier navigation - We've made it simpler for everyone to use the site and find the information they need:**

- New accessibility tool which enables people to change the sites font size, colours, removed images and more
- Improved layout with better links to related content
- Text is now easier to read, with accordion-style sections for clarity
- Fully mobile and tablet-friendly for easier browsing on the go
- Added a "Latest News" section so visitors can easily see what has recently been updated or changed

2. **Region-specific support and services** - We added more tailored information for both Northern Ireland and the Republic of Ireland.

- Pages include country-specific advice or links where needed.
- A new "Support and Services" section helps users find local help more easily.
- Links provided to Citizens Information, NI Direct, HSE, Carers UK and other regional organisations where relevant.

3. **Expanded content based on carer needs**

- New pages created including: Mental Health & Emotional Support, Respite Care & Taking Breaks, Legal & Financial Advice, Advance Care Planning, and Mindfulness & Self-Care.
- Practical advice on topics like managing medication, personal care, safe home environments, and nutrition.

- Bereavement section includes practical support and emotional guidance.

4. More multimedia and practical formats

- Embedded videos, podcasts and downloadable resources have been added where appropriate.
- Real-life tips and quotes from carers are woven throughout content.
- Complex topics broken down into bite-sized, practical guidance.

Appendix A

Health and Social Care Professional Focus Group Questions

1. What subjects or information should be added to the website around caring for someone with palliative care needs/a life-limiting condition?
2. Are there services or tools you think should be included on the website to improve its usefulness for carers?
3. What kinds of resources, like publications or guides, would you find helpful to see added to the website?
4. What changes to the site's navigation, layout, or design would make it easier to use?

AIIHPC's Voices4Care volunteer group Focus Group Questions

1. What aspects of palliative care do you feel are most important/helpful to be represented on a dedicated website?
2. Is there any content that you find/found hard to locate online that we should prioritise?
3. What are the biggest challenges you face in accessing palliative care resources and information for carers online?
4. Are there particular resources (e.g., articles, videos, support groups) that you believe should be prioritised?
5. What features would make it easier for you to find the information you need?

Appendix B

1. **What is your role in relation to palliative care?**

- Health and Social Care Professional
- Family member/carer
- Someone with a life-limiting condition
- General public
- Other

2. **Have you visited The Palliative Hub – Carers website before?**

- Yes
- No
- I'm not sure

3. **Please rate the following design and accessibility features of the current website:**
(Scale of 1 to 5 where 1 = Very Poor, 5 = Very Good)

- Colour scheme
- Font style
- Design and layout
- Ease of use/navigation
- Content clarity
- Accessibility features (e.g. for screen readers, font size adjustments)

4. **Please rate how well you think the current site communicates information and services for carers of people with palliative care needs.**
(Scale of 1 to 5)

- 1 = Not at all
- 5 = Extremely well

5. **Which of the following areas do you find most helpful on the site? (Select all that apply)**

- Caring for someone at home
- Symptom management
- Taking care of your own mental health
- Bereavement and loss
- Where to find help and services
- Financial/legal matters
- Understanding palliative care
- Other (please specify)

6. Do you feel the language and tone of the website is appropriate and inclusive for carers?

- Yes
- No
- I'm not sure

7. **How useful do you find the following types of content or features?**
(Scale of 1 to 5 from “Not at all useful” to “Very useful”)

- Videos
- Podcasts
- Real-life stories and quotes
- Chatbot to help find information
- Plain text pages
- Interactive activities (e.g. self-assessments)
- Images or animations

8. **Would you recommend The Palliative Hub – Carers website to someone looking for information on palliative care?**

- Yes
- No
- I’m not sure

9. **What do you think could improve the website for carers?**
(Open-ended response)

10. **Do you have any other comments or suggestions?**
(Open-ended response)