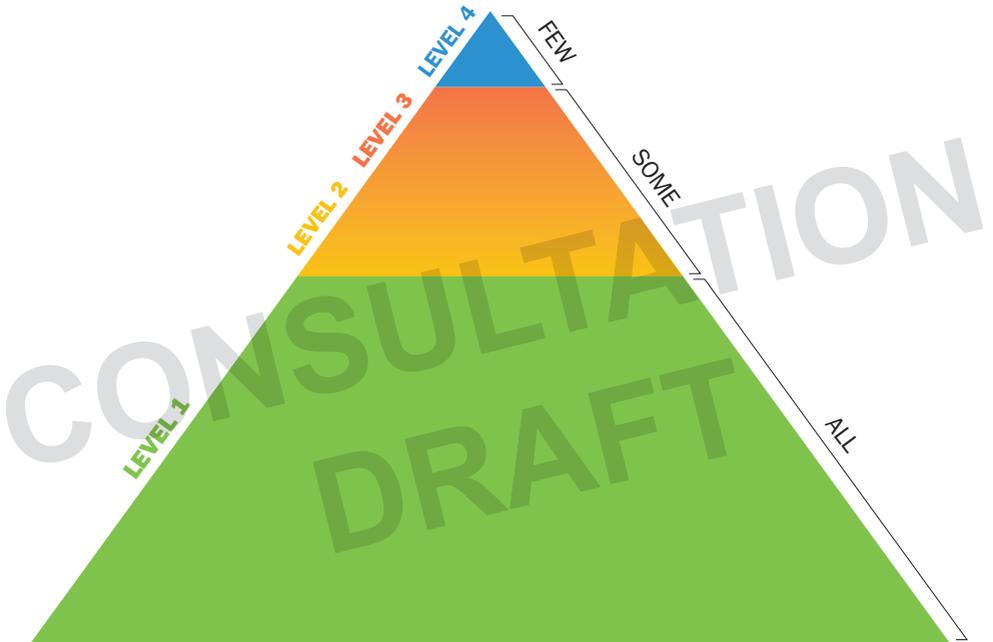


THE IRISH ADULT BEREAVEMENT CARE PYRAMID

Developing a national framework



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Consultation document
October 2019

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Developed by



CHY 6830

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In collaboration with



In the absence of a national approach to adult bereavement care in Ireland, the Irish Hospice Foundation facilitated a national collaborative process to develop a framework for adult bereavement care in Ireland¹.

This tiered framework was developed to guide those working and supporting bereaved people in Ireland. It aims to help those who meet people who are bereaved in their day to day work (e.g. General Practitioners, Citizen Information Service etc.) and those who provide direct bereavement support (i.e. from information, group or individual support, counselling to mental health professionals) to identify and respond appropriately to adults who have experienced a loss.

DEVELOPMENT OF THE FRAMEWORK

The *'Enhancing Adult Bereavement Care across Ireland'* report of a national consultation was published in 2018² and identified a common set of core concerns among those who encounter bereaved people as part of their work. The lack of a common framework for bereavement care in Ireland was identified and prioritized by the report's project advisory committee (PAC)³.

In considering the report findings (which included a literature review and consultation with service providers across the country) and the evidence for a public health approach to bereavement care, the PAC adapted the Irish Childhood Bereavement Care Pyramid for adult bereavement care. This tiered pyramid-based framework, along with the report findings, was presented at the third National Bereavement Forum (NBF) in June 2018 hosted by the Irish Hospice Foundation. Forum attendees engaged in a structured feedback process.

¹ Adapted from the Irish Childhood Bereavement Network's Childhood Bereavement Care Pyramid: <https://www.childhoodbereavement.ie/professionals/childhood-bereavement-care-pyramid/>

² https://hospicefoundation.ie/wp-content/uploads/2018/07/Enhancing-Adult-Bereavement-Care-Across-Ireland_REPORT.pdf

³ Advisory group were organisations represented at the Forum 2019 – Barretstown, Bethany Bereavement Support Service, FirstLight, Mater Misericordiae University Hospital, Palliative Care North East, Pieta House, The Irish Hospice Foundation.

Subsequently, a short term project committee was set up in September 2018 to develop this framework further. The committee members stemmed from organisations represented at the 2018 National Bereavement Forum and included representatives of providers at all levels of service provision, both State and NGO sector and from organisations across the country⁴.

The current framework will be finalized through a final consultation process. The framework, accompanying leaflet and a survey is being sent via SurveyMonkey to services/supports at all levels of the pyramid, both the statutory and the NGO sector and will include national, local and international stakeholders⁵.

This has been a collaborative process which has been project managed by the Irish Hospice Foundation (supported by the Health Service Executive). This framework places bereaved people's needs at the centre and sets out to clarify the appropriate support/services and competence required to meet basic through to complex bereavement needs.

⁴ Barretstown, Bethany Bereavement Support Group, Citizen Information Service, Department of Health (Mental Health), Feileacain, FirstLight, Galway University Hospital, HSE (Mental Health), Pieta House, MOCT Training and consultancy, St Francis Hospice, Trinity College Dublin, The Irish Hospice Foundation.

⁵ For example, Age Action, College of Psychiatrists of Ireland, Counselling in Primary Care, European Bereavement Network, Irish Association of Funeral Directors, Irish Association of Social Workers, Irish College of General Practitioners, Irish Road Victims Association, SAGE, Samaritans, Support After Homicide.

HOW TO USE THE FRAMEWORK

The framework is based on a pyramid model which suggests that **ALL** people who experience a bereavement have some level of **NEED**, such as the need for compassion and acknowledgement of the death (**LEVEL 1**). **SOME** need additional support which is outside their natural network, such as peer to peer support (**LEVEL 2**). **SOME** require a more intensive support, such as counselling (**LEVEL 3**) and a **FEW** require support from a specialist therapeutic service (**LEVEL 4**). It is important to note that people may access more than one level of support at one time (e.g. Someone may access financial advice services for financial difficulties (Level 1) and attend a mental health professional for a grief reaction which impacts on their daily functioning).

In addition to identifying the varying levels of **NEED** experienced by those who are bereaved, the framework also outlines the **SUPPORTS/SERVICES** appropriate to meet each level of need and the recommended **KNOWLEDGE/SKILLS** required by those providing support at each of the four levels. For example, a person who is bereaved may need to explore grief with someone outside their natural network (need at level 2), thus may benefit from accessing a one-to-one or group community-based bereavement service where they can reflect on their bereavement in a more focused way (supports/services at level 2). The service provider at level 2 should have an understanding of the impact of loss; have listening and empathy skills; be able to ascertain if the bereaved person needs a higher level of service provision (i.e. level 3 or 4) and some knowledge of bereavement services available. A service at this level should have some formal quality assurance process in place.

This framework acknowledges that the **SOCIAL NETWORKS** of the bereaved person, the **CIRCUMSTANCES** surrounding the loss and **TIME** play a role in the experience of bereavement. The social networks refer to the support provided by people in the bereaved person's social network. It is important that the person considers the support they receive from their network as helpful. Circumstances surrounding the loss can refer to a variety of things including the circumstance of the death itself, the bereaved person or the relationship to the deceased. All of which impacts the experience of bereavement. Time also plays a role in the experience and can include the amount of time since the death or the time in a person's life the death occurs.

Although many bereaved can adapt to the loss with level 1 support some need the more intensive supports available at the higher levels. The referral and signposting services at level 2 are integral to the framework as they can ensure a person accesses the appropriate level of service provision to meet their needs. Thus, good assessment is key to identifying the level of support/service that would best meet the needs of the person. Supports/services at all levels should be available and accessible to all that need them and access should not be restricted due to geography or cost. It is important to note that a person's needs can evolve and change over time.

THE ADULT BEREAVEMENT CARE PYRAMID

LEVEL 1

ACKNOWLEDGEMENT, SUPPORT & INFORMATION

Acknowledgement of the loss and a compassionate response. The need for the death to be acknowledged and a compassionate response from family, friends, professionals and the wider community.

Practical and emotional support. These supports can include someone to listen or cook a meal. It is important that the person deems the support received as helpful.

Information (e.g. practical, emotional, services). Information can include: practical information, such as how to register a death; information about the various reactions to loss including emotional reactions and information about more formal supports/services available.

INFORMAL SUPPORTS & ACCESSIBLE INFORMATION

Provided by the natural support network. Support and information should be provided by people in the person's natural network of support (e.g. family, friends, work colleagues) and professionals around the time of death (e.g. hospital staff, funeral directors, social protection staff).

Easily accessible information. Information about aspects of bereavement should be easily accessible. For example, it should be available in different languages and available via a wide range of mediums from written resources, online, phone and local information events. Ideally information should be accessible through a national resource and should signpost users to the relevant resources/services.

Widely available. Support and information about bereavement should also be available within the wider community (e.g. information agencies, GP surgeries etc.). However, it is acknowledged that some initiatives need to take place prior to this being the norm (e.g. public awareness campaigns about the process of grief) to ensure everyone receives a compassionate response when a death occurs.

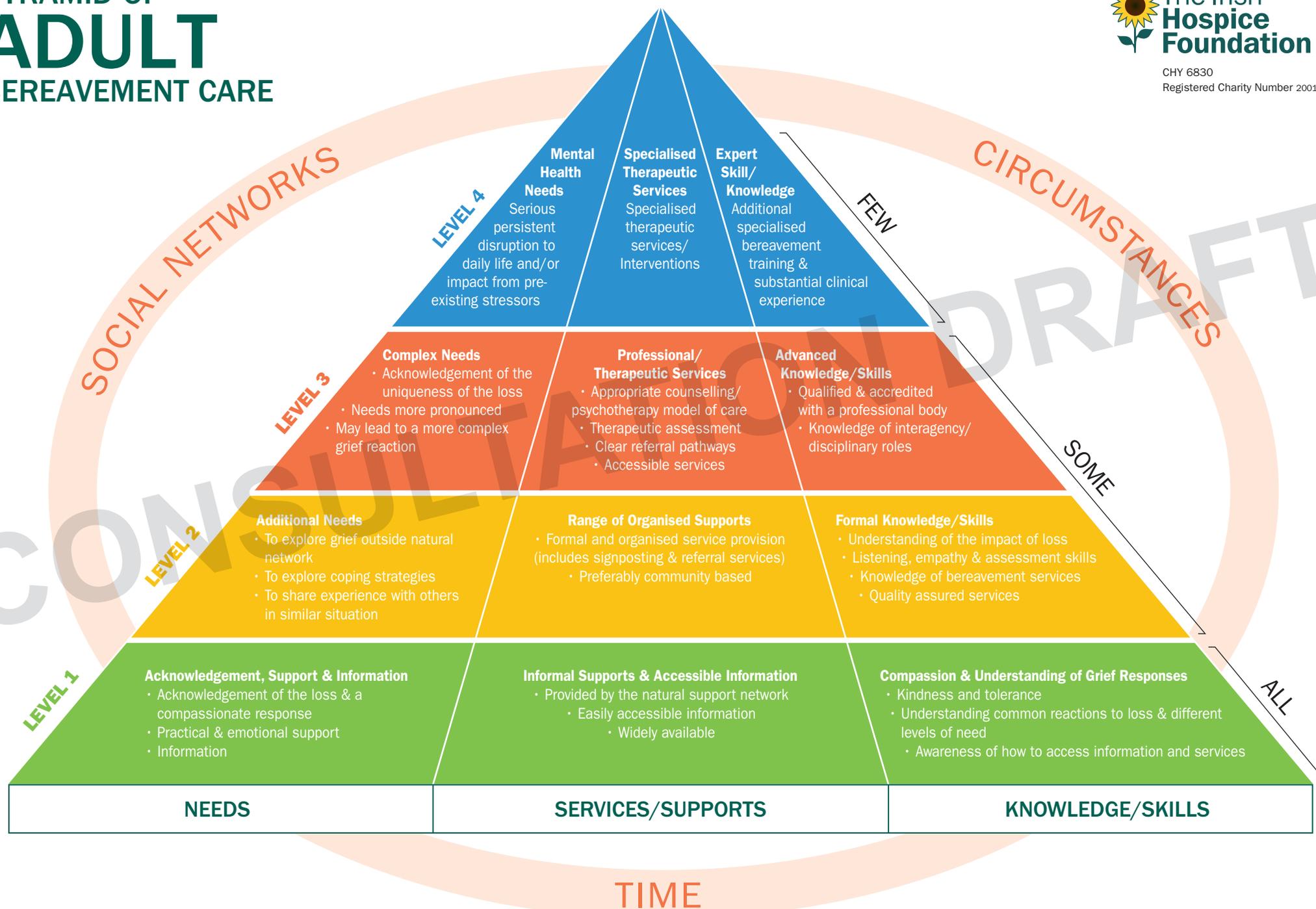
COMPASSION AND UNDERSTANDING OF GRIEF RESPONSES

Kindness and tolerance. The ability to show compassion, kindness and tolerance. All gestures, big or small, can have a positive impact on someone's experience of a death and bereavement.

Understanding of common reactions to loss and the different levels of need. An understanding of the variety of ways people can react to a loss, including reactions that are common and those that require a more formal level of support.

Awareness of how to access information and services. Knowledge of when people require a higher level of support and awareness of how to access appropriate services to meet their needs.

PYRAMID OF ADULT BEREAVEMENT CARE



LEVEL 2

ADDITIONAL NEEDS

Need to explore grief outside natural network. Needs at this level move from the generic, to a need for a more individualised and interpersonal response. The person may feel unable to cope, may feel isolated from or not have access to a natural support network. They might find going through the details of the death or the relationship with someone who is outside the family helpful. Needs can be both emotional and practical, they may evolve overtime, requiring information more specific to the situation e.g. linking in with an organisation specifically for those who experience a traumatic death.

Need an opportunity to explore coping strategies. This may include looking at past, present and possible future coping mechanisms and learning new skills. It might involve meeting a person with bereavement specific training to explore possible ways to cope with overwhelming feelings or reflect in a more focused way on their experience of loss.

Need to share experience with others in a similar situation. Some people feel isolated in their experience and seek to share their grief with others in a similar situation.

RANGE OF ORGANISED SUPPORTS

Formal and organised service provision (includes signposting/referral services). Services at this level range from providing targeted information, signposting or referral to other services, to providing the service. Healthcare professionals, such as the GP or public health nurse can signpost to the appropriate support service. Services may operate on an outreach basis (i.e. offered to those who fit particular profile/ bereavement need), an in-reach basis (i.e. open to those who approach the service through identifying their own need) or through referral.

Preferably community based. Services at this level are preferably offered within the community. Services may include: bereavement peer support, listening services, bereavement programs. Services at this level offer information and support in a more formal and personalised way. For example, information about the bereavement process may be provided

one-to-one by a person with bereavement specific training. Thus, additional emotional support is offered in a more formal way than the natural network. These community-based services should be available to people as and when their need arises regardless of the time since death.

FORMAL KNOWLEDGE/SKILLS

Understanding of the impact of loss. Level of knowledge should be appropriate to role, scope of practice, level and type of service provision. There is a continuum of knowledge with regards to bereavement required at level 2 as it includes a wide range of services. Services require clear awareness and understanding of how bereavement can impact emotionally, physically and practically.

Listening, empathy and assessment skills. Services should have the ability to provide tailored support based on compassionate listening. Active listening and assessment skills are needed which recognise the appropriate next steps or referral pathways.

Knowledge of bereavement services. Those who signpost services, such as GPs, should be able to assess service level need and have knowledge of local service provision.

Quality assured services. Governance, safeguarding and quality assurance systems should be in place for service providers appropriate to their scope of practice. These might include policies, supervision, training, scope of practice, developed referral pathway etc.

LEVEL 3

COMPLEX NEEDS

Acknowledgement of the uniqueness of the loss. Needs in bereavement are unique and individual and they may evolve and change over time.

Needs are more pronounced. At level 3, needs from earlier levels may be more complex and intense. Coping resources may be so stretched that in these circumstances a person may require external help. Needs can be more complex due to one or more of the following factors:

- Impacts of loss combined with other life stressors (e.g. social/family/practical or financial complexities) may be experienced as overwhelming.
- Ongoing issues with physical or mental health combined with the loss can lead to increased vulnerability
- The context and circumstance of the loss (e.g. sudden death, nature of death, nature of relationship) can mean emotional and practical transitions are particularly challenging. In these circumstances a person may require help with adapting.
- There may be 'secondary' losses experienced by a bereaved person/family – which may include loss of support, loss of friends/network, loss of income, loss of role (e.g. a carer), loss of career, loss of confidence etc.

May lead to a more complex grief reaction. If these needs are not addressed they may lead to a more complex reaction over time.

PROFESSIONAL/THERAPEUTIC SERVICES

Appropriate counselling/psychotherapy model of care. These therapeutic interventions/model of care must be appropriate to meet the identified need. Responses and services should be evidence-based.

Therapeutic assessment. Assessing need should be a collaborative problem-solving process in order to ensure appropriate service response. Service providers should be aware that the assessment itself can be a helpful intervention. Assessment should be holistic focussing on practical, emotional and psychological impacts.

Clear referral pathways. In order for services to be accessible and appropriate there should be a shared understanding of their purpose and a clear pathway to access them. Some supports are accessible by bereaved people themselves through self-referral and others require a formal referral through a third party.

Accessible services. Appropriate services at this level should be accessible regardless of location or ability to pay. These services should also be provided through a range of media – face to face, online, telephone etc.

ADVANCED KNOWLEDGE/SKILLS

Qualified and accredited with a professional body. Service providers at this level should possess the knowledge and skills of supports at level 2. However, level 3 providers should also have an accreditation with a professional body which promotes ongoing continuous professional development (CPD), including bereavement specific training, regular supervision and professional indemnity insurance for those working with people therapeutically. Service providers should have a qualification in counselling or in counselling skills.

Knowledge of interagency/disciplinary roles. People providing level 3 support should have knowledge about the range of available supports and the roles of other professions or agencies in supporting bereaved people. Professionals working at this level should be aware of and recognise signs of Prolonged Grief Disorder (PGD)⁶ and refer on appropriately.

As with level 2 supports, services at level 3 should have governance, safeguarding and quality assurance systems in place appropriate to their scope of practice.

LEVEL 4

MENTAL HEALTH NEEDS

Serious persistent disruption to daily life and/or impact from pre-existing stressors. Needs at this level are more complex and are identifiable in that they impact on the day to day functioning of the person. Needs may present as:

- Acute and require immediate professional intervention (e.g. self harm, suicidal ideation);
- The bereavement may exacerbate a pre-existing mental health issue e.g. addiction, depression; or
- Chronic, in that the intense grief reaction may develop over time (e.g. Prolonged Grief Disorder or Persistent Complex Bereavement Disorder).

⁶ For further reading refer to Boelen & Smid (2017) Disturbed grief: prolonged grief disorder and Persistent Complex Bereavement Disorder, BMJ, 357 <https://www.bmj.com/content/357/bmj.j2016>

Factors to consider when assessing for Prolonged Grief or Persistent Complex Bereavement include: symptom duration, separation distress, impact on important areas of functioning (e.g. family, personal, education, occupational, social), other bereavement specific symptoms (e.g. a desire to die, to be with the deceased; feeling alone and detached from others; excessive avoidance of places, people or objects reminding of the loss) and a reaction out of proportion or inconsistent with the normal expectations of an individuals community (e.g. social, cultural, religious).

SPECIALISED THERAPEUTIC SERVICES

Specialised therapeutic services/interventions. As with services at level 3, level 4 services should have clear referral pathways and be accessible at any point in the grief trajectory. Thus, it is important that signposting/referral services at level 2 are aware and recognize when someone requires level 4 service provision⁷. The model of care should be evidence-based and set within specialised services. It includes but is not limited to the identification and treatment of Prolonged Grief Disorder (PGD, ICD-11) and Persistent Complex Bereavement Disorder (PCBD, DSM-5).

EXPERT SKILL/KNOWLEDGE

Additional specialised bereavement training. As with level 2 and 3 services, services at level 4 should have governance, safeguarding and quality assurance systems appropriate to their scope of practice in place; service provision by qualified staff accredited with a professional body; and knowledge about the range of available supports and additional roles of other professionals or agencies in supporting bereaved people. Professionals at this level should refer to evidence based and contemporary knowledge in their work, for example, evidence based treatments for Prolonged Grief Disorder.

Substantial clinical experience. Service providers should have clinical experience in supporting people with a clinically significant grief reaction. The service should also be provided within the context of a multidisciplinary team.

⁷ People experiencing distressing and disabling grief reactions six month on from the loss might benefit from psychological interventions. Those who experience a traumatic bereavement or have other mental health conditions may need help sooner.