Future Transitions In Palliative Care

Care Across the Life Course for People with Life-Limiting Conditions

Contents

Background

Funded by the Scottish Universities Insight Institute (www.scottishinsight.ac.uk), this programme explored the future of palliative care transitions for people with life limiting conditions. The programme aimed to build a contextual understanding of care needs and aspirations across the life course and scope future care models that support the development of person-centred care towards Scotland 2030. There is a need to focus on positive and preferable destinations of care where the ethos and values of services provide a seamless transition for people with life limiting conditions, regardless of life stage.

Transitions of care are not simply focused on the person receiving care but also the wider care circles, such as family, friends, volunteers, practitioners delivering care, as well as policy and decision makers who impact the care experience. As such, the programme brought together the existing active networks of cross sector organisations, practitioners, families and people with lived experience of services together, ensuring all voices are heard.

The programme is a multi-institutional collaboration led by The Glasgow School of Art and the University of Dundee.

The programme provides a way to build the foundations for innovation in palliative care pathways for people with life limiting conditions at the 'front line' at points of transition to set the direction towards 2030. Our approach is underpinned by the need to develop innovations based on the 'right' conditions and principles by placing interactions between people and their care circle at the core of care delivery to enable conversations that are centred around aspirations for care and thus contribute to seamless transitions for people of all ages.

Programme Aims

Bringing together a multidisciplinary team, and directly involving people with life limiting conditions and their families and carers, this programme aimed to explore and understand the care context and needs during particular life stages and transitions towards achieving person-centred palliative care. Using a design-led approach the programme explored preferable future scenarios that create sustainability for communities and improve quality of life for people and their families.

The key objectives of the programme were:

·   To provide a platform to bring forth the lived experiences of people with life limiting conditions and those who have been impacted by life limiting conditions, alongside other views and experiences to inform what meaningful care should be.

·   To facilitate knowledge exchange among academics, health and social care professionals, education and third sector practitioners, volunteers, and policy and decision makers, with a view to provide person-centred palliative care across the life course.

·   To consolidate the insights generated through creative engagement across the interactive seminars to identify research, practice and policy priorities for future needs across the life course for people with life limiting conditions and their families.

Programme
Team

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The programme also had 6
participants who were engaged
through the 'Flurries'

Methodology

The programme employed a design-led approach to a series of creative engagements to bring together the programme team, participants and other external partners to explore and roadmap future palliative care transitions for Scotland 2030. The creative engagements provided a space to share research evidence (Creative Seminar), gather lived experiences from people with life limiting conditions, and from their wider circles of care including family, and practitioners (Flurries); and facilitate knowledge exchange by bringing these stakeholders together with policymakers, to identify key policy and practice priorities for meaningful future palliative care needs across the life course (Co-design Workshop).

The development of a creative and participatory design approach was a central element of the programme in stimulating productive discussion through the creative seminar, flurries and co-design workshop. The Flourish process (McAra-McWilliam et al., 2014) informed the intent of the programme by embedding qualities of life, personhood and collective wellbeing at the heart of the engagements. The open and emergent process provided flexibility to allow the programme to grow in terms of the thematic areas explored, and expand the range and diversity of participation. The differing scale of participation


(from one to one engagements to large scale co-design) across the programme events allowed us to create spaces bespoke to the context of each engagement and participant group.

Across the programme this approach allowed us to integrate lived experience, research, practice and policy perspectives to provide an inclusive space for knowledge exchange and co-design. The use of visual and participatory design methods supported creative exploration and sustained motivation and engagement.
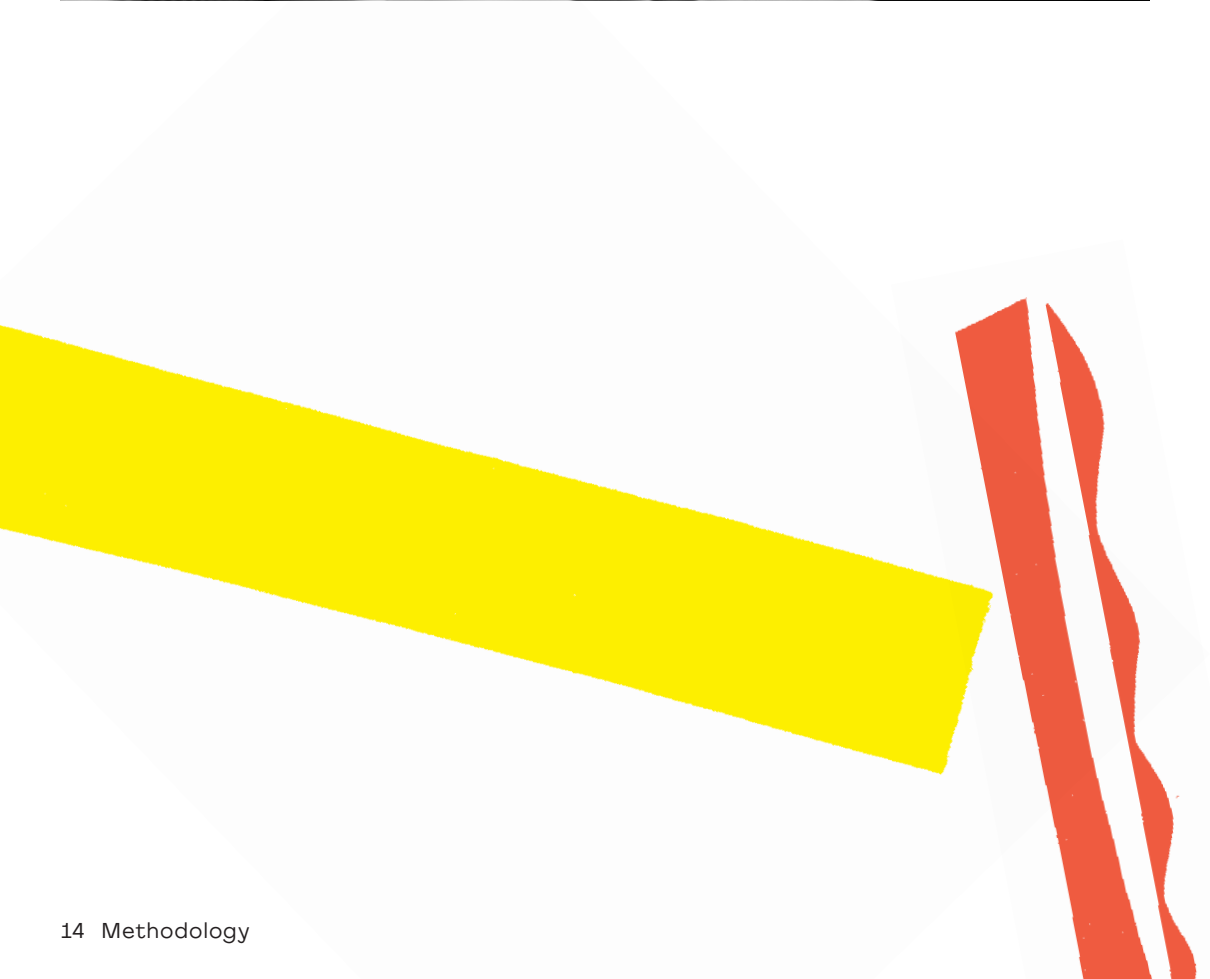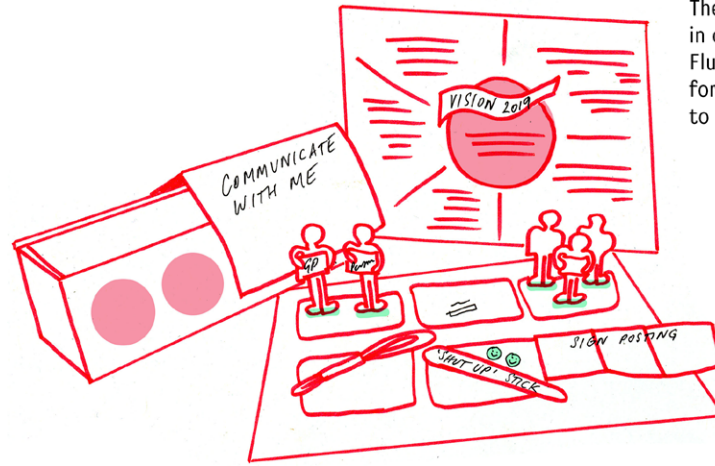
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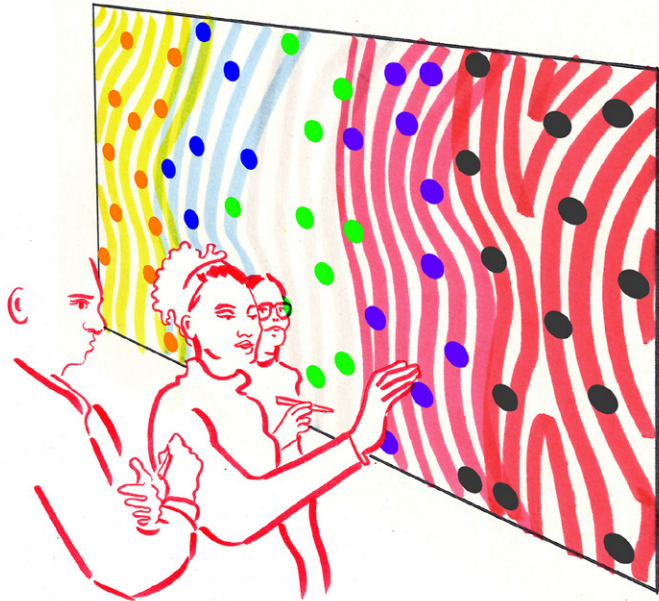
Creative Seminar: Understanding the Context

In the creative seminar we explored transitions in palliative care by unpacking current research, practice and policy with a diverse group of participants including academics, practitioners, policy leads and advisors, students and one participant with experience of caring for a family member. Visual tools were created to allow participants to map their expertise and relationship to transitions (see page 14) and to build a contextual understanding of the current landscape of research, policy and practice.
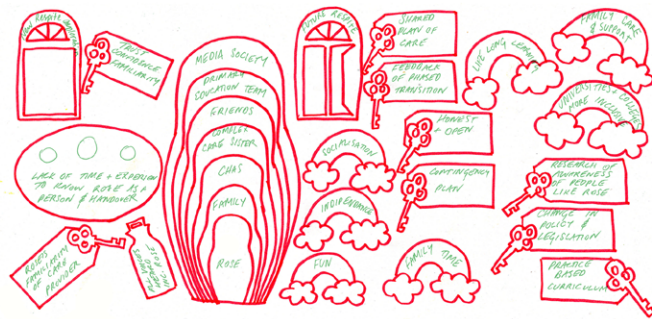
The Flurries: Lived Experiences of Transitions

The flurries allowed for intensive and immersive engagement in small groups to understand individual experiences of palliative care transitions and to situate the insights emerging from the seminars in context, crystalise narratives and insights, and bring the voice of lived experience to the co-design workshop. The first set of flurries engaged participants on an individual basis to share their personal experience and then participants were brought together in a later flurry to explore collective experience. The use of metaphor and visual tools allowed participants to share their experiences in a sensitive and personal way. Using the analogy of open and closed doors, magic potions and rainbows, people shared their challenges, stories of what works well and their aspirations for future transitions.

Co-analysis: Synthesising Key Themes

The programme team were engaged in a collaborative analysis session in order to cluster and synthesise the insights from the Seminar and Flurries. The emerging themes were prioritised based on opportunities for developing ideas for future transitions and the expertise of the team to develop six co-design briefs to inform the activities in the final workshop.

Co-design Workshop: Vision and Roadmap for Future Transitions in Palliative Care

The workshop engaged participants in an immersive co-design session to work together to creatively respond to emerging themes towards co-designing future transitions in palliative care. Participation was largely sustained from the first Seminar, and further grew as a result of the dissemination of the outputs from the Seminar and Flurries. The narratives of lived experiences collected in the flurries were visualized as stories, and shared within the workshop to inspire collaborative development of preferable visions of future palliative care transitions. We used visual tools and playful materials to support groups to explore and prototype responses to the co-design briefs.
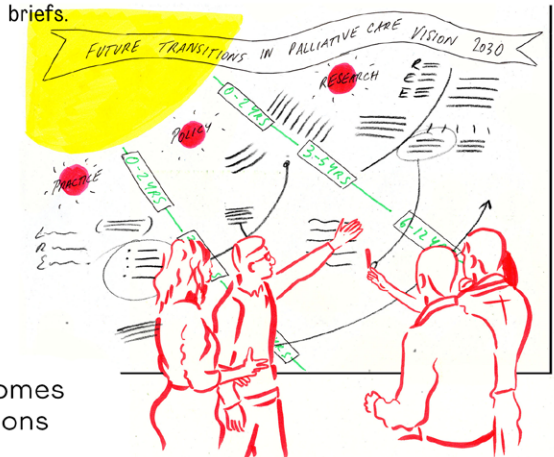
Co-analysis: Outcomes and Future Directions

A final co-analysis session was organised with the programme team to identify and articulate key learnings, priorities and recommendations for research, policy and practice.

Findings

A number of key themes emerged from the analysis of insights across the programme.

Normalising Language and Terminology

The theme of terminology, language and rituals recurred in all engagements across the programme. Definitions of terms such as 'palliative care', 'end of life care', and 'hospice' were often perceived to be not well understood in general. As a result, stigma of what these terms mean can impact decisions, awareness and access to support. The lack of clarity in definitions and the varying interpretations of these by professionals also has implications in practice for referrals to appropriate palliative care services. The need to normalise and clarify definitions of terms was highlighted as a key towards creating better understanding and uptake of care. In addition, the need to use realistic language and talk openly about 'death and dying' would help to change conversations and make it acceptable to acknowledge loss and support bereavement, as well as help prepare people to cope with the end of life. It was highlighted that policy has a key role to play in setting the tone around language and terminology in order to support awareness and understanding among the public and all stakeholders involved in care.

A Key Moment:
The Point
of Diagnosis
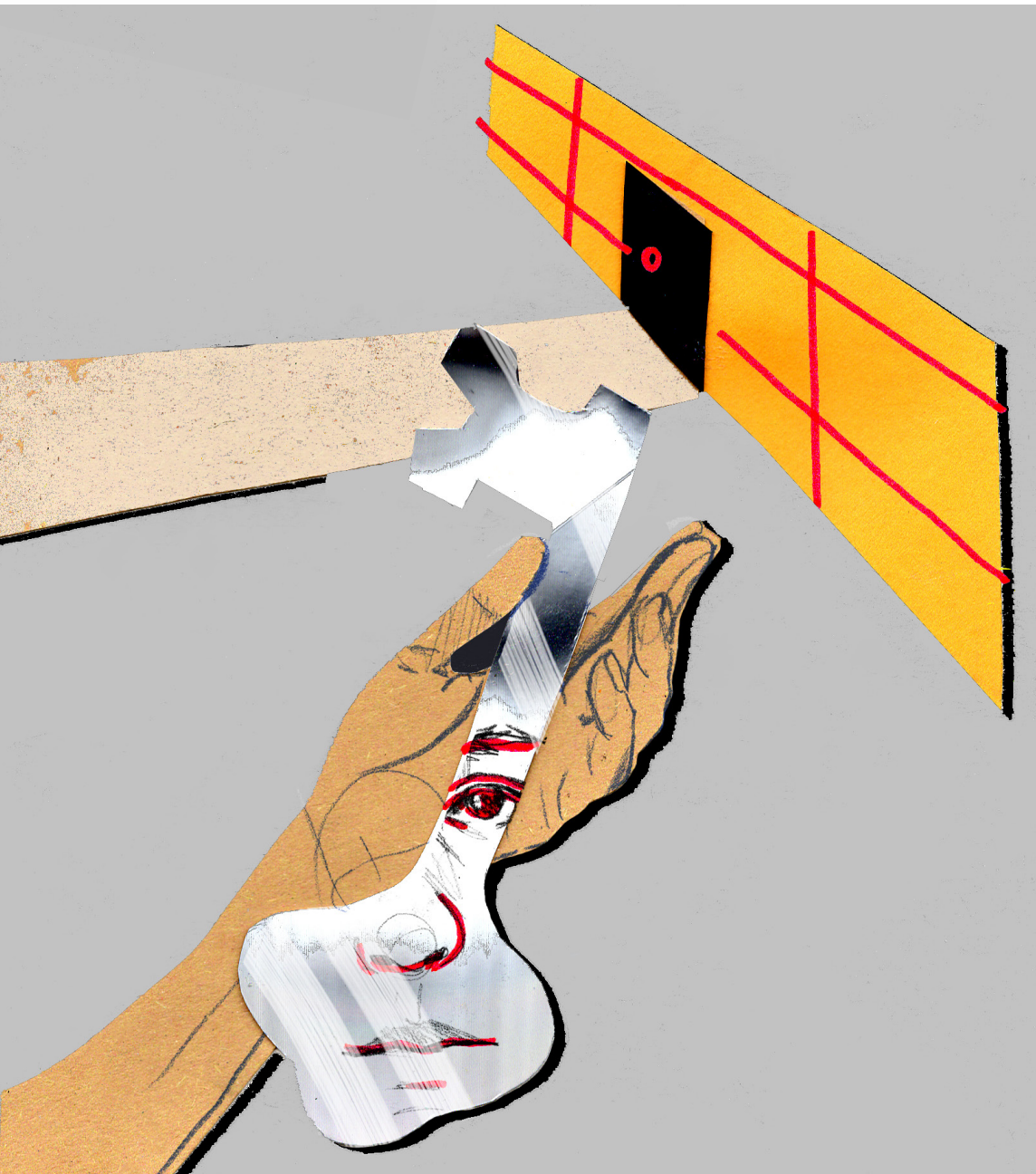
The point of diagnosis was described as a key moment that determines the journey for individuals with life limiting conditions and their families and is a time of significant transition. It is important to see this as a holistic journey that is more than the clinical pathway and takes into account the physical, mental and socio-cultural transitions that will be experienced. The point of diagnosis was described as 'sudden' 'unexpected', and 'harsh' and where people can feel 'hopeless', 'abandoned', 'trapped' and 'isolated'. There is a need to move the diagnosis beyond a conversation to a process that is responsive to the pace at which a person can cope with the diagnosis. Crafting key decisions at the right moments is key to this process as each decision at this stage will have an impact on the rest of the journey. In practice, empathetic attitude and an awareness of the power balance in interactions between professionals and people with life limiting conditions and their families was seen as important throughout the journey but particularly crucial at the point of diagnosis. This includes ensuring support for grief and trauma; the range of emotions and uncertainties that are experienced by the person and their family; and adapting to a new way of living with a life limiting condition.

Shifting Identities

When diagnosed with or living with a life limiting contition the person and their family often experience a shift in identities. They may experience a loss of identity in relation to personal, social and professional circumstances, e.g. career, independence, relationships, and choice; and they may experience a shift in identity, e.g. from partner to carer. Labels such as 'patient' and 'carer' add to a sense of loss of individual identity and power, therefore, in practice it is important to acknowledge the relationship as 'people working with people' and recognise them for who they are rather than reduce their identity to their condition. For example, it was highlighted that it can be difficult for parents of children/young people with life limiting conditions to maintain their role being parents in a clinical setting. Building a culture of care that acknowledges and supports shifting identities will support an enriching learning journey and build confidence over time for both the person and their families.

Support from Volunteers and the Wider Community

The wider community and volunteers have a key role to play in supporting transitions for people and their families. Transitions involving changes in existing social circles were prominent for many and this includes not just the loss of social contacts but also leads to formation of new relationships through increased interactions with professionals and the wider care community. These new 'circles of care' can support the person to adjust by providing compassion and a resource for accessing 'social' support that can allow the person to continue 'living life'. Policy should support more involvement of volunteers by ensuring they are valued, trained, supported and funded. The idea of a 'community compass' as a type of transitions team that supports people to navigate their journey to get the right support at the right time emerged in relation to this theme. It was suggested that a collaborative approach to care could be achieved by integrating communities as part of the existing multidisciplinary team.

This would require creating supportive environments and removing risk aversion to promote increased involvement of volunteers. In addition, health and social care partnerships need to play a directive role in understanding the landscape of services and support available.

The voice of lived experience was highlighted as invaluable to empower people and enrich their journeys, as 'services serve' and do not currently mainstream the learning from lived experiences. The lived experience of people with life limiting conditions and their families and shared experiences of volunteers and the community provides opportunities to learn from and support each other as well as to train health and social care professionals. Knowing someone who has experienced a service or recommendations from friends who may have connections to services can help people seek support.
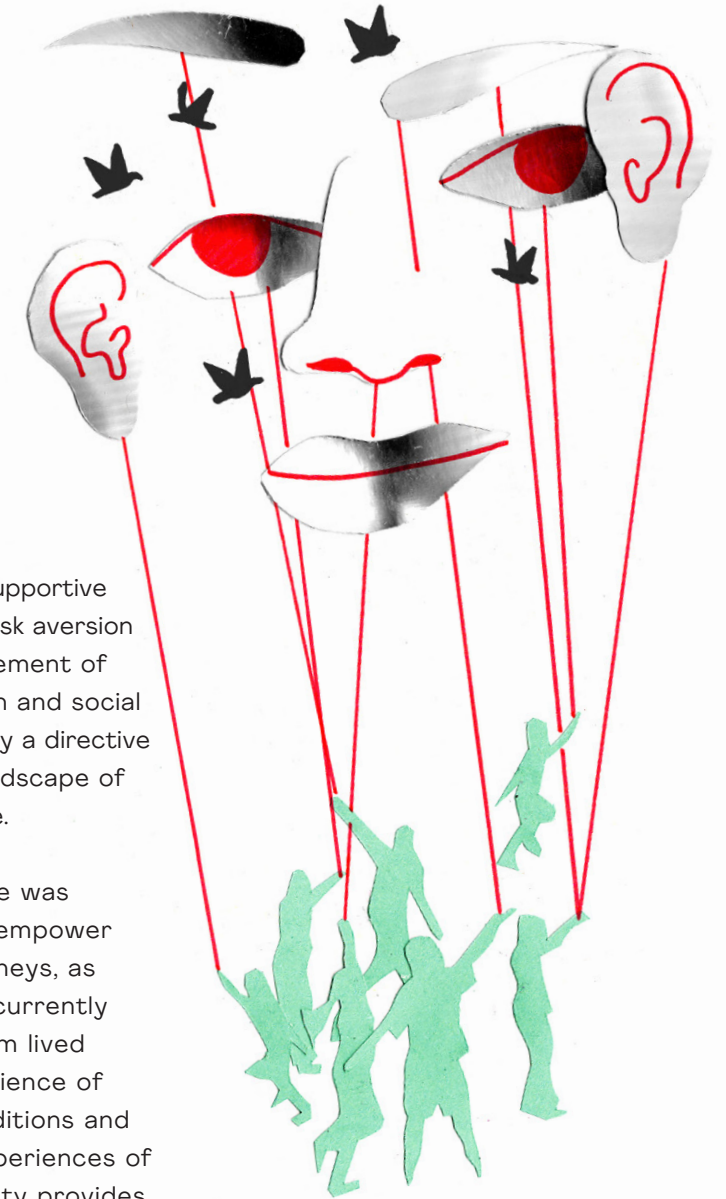
Including All Voices and Aspirations

Ensuring that all voices are heard, and placing hopes, aspirations, needs and capabilities of the person at the centre of care is key to a relationship-based, person-centred practice. To ensure equity, respect and dignity in care for all at the end of life, rather than increased coverage, there is a need to identify and reach out to those who do not have the resources, skills or confidence to engage, and those who are unable to recognise their need for support in addition to people who already seek support.

This will require an understanding of where there are gaps in service provision; developing new ways to overcome barriers such as lack of verbal communication or 'deskilling' of people because of their condition or circumstances; and addressing power imbalances. Practice-based curriculum for future nurses and carers was suggested as a way of supporting them to involve people, build relationships and familiarity, and learn from the lived experiences of the person and their family. Respecting and valuing the person and their family
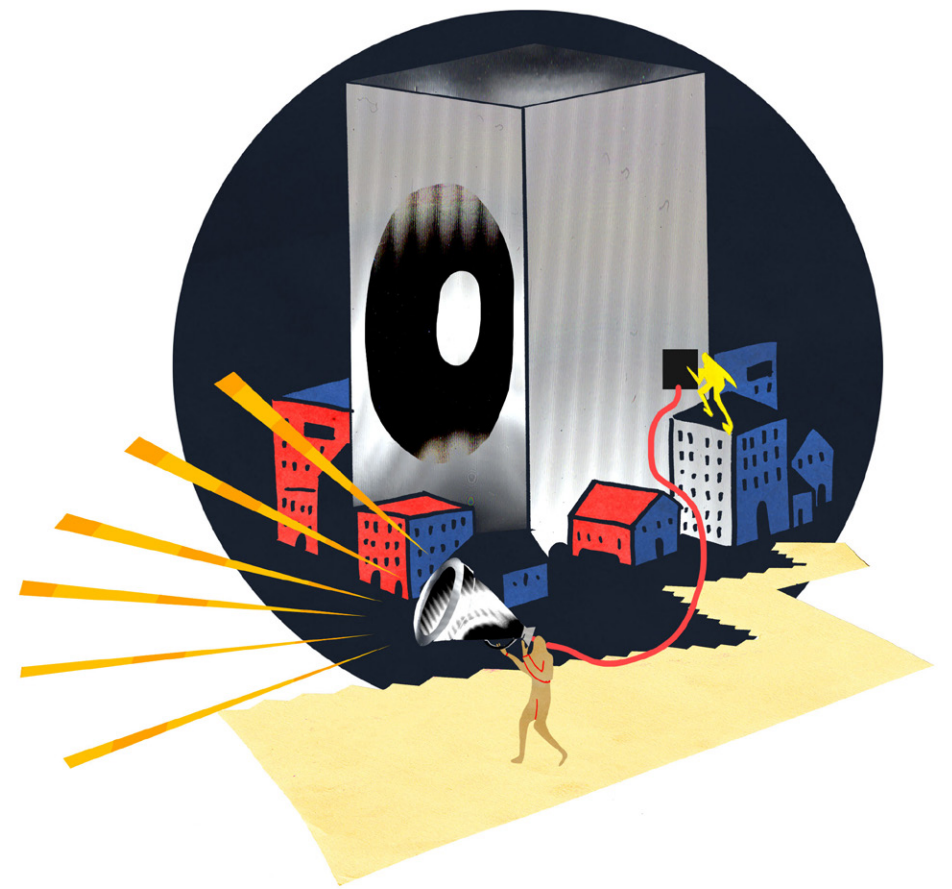
is important for understanding the 'ecology' of every stage, situation and cultural differences in palliative care policy and practice.

People living with life limiting conditions, especially children and young people, aspire to be fully included in all aspects of society. This involves taking into account young people's needs for independence, achievement, fun and opportunities for life long learning. It emerged that there is a need to increase awareness and develop new ways of how society can integrate and care for all people with palliative needs. Policy and practice should promote inclusivity across all educational institutions and employers.

Quality of Care for Quality of Life

An important aspect of living well and having quality of life requires both quality and quantity of care for the person and their family. Good relationships among people, families and their care providers, communities and other organisations is an important aspect in relation to quality of care and the transitions that occur. Qualities of good care include love, honesty, trust, confidence, familiarity, personal, one-to-one time, support and feeling safe. Respite was highlighted as integral part of survival, healing and wellbeing and provide opportunities for socialisation, fun and independence for the person and family.

Policy and strategy should recognise that as people are living longer they spend more time moving between different services and environments and it is important that these offer a sense of 'normality' that is not unfamiliar or intimidating to support achieving quality of life. It was highlighted that access to respite care is most important during difficult transitions and a lack of access can have an adverse impact on wellbeing of the person and their family. There is a need to look at the health economics of respite care and how this could lead to additional benefits for the health and care system. Ensuring that multiple and multi-dimensional transitions are as seamless as possible for all was a key message to enable quality of life through quality of care. Basing care and services around stages of a person's palliative care journey rather than their age was recognised as key to achieving consistency in quality of care for all. The need to build care around the person's needs and feelings, existing strengths in personal and family networks, and working in partnership with families were also highlighted as ways to "Getting it right for every death". Policy to support end of life experience (e.g., a Charter for End of Life) should take into consideration personal choice on place of death (e.g., home, homely, hospice, hospital), and reassess whether all places where people spend their end of life are fit for purpose (e.g., prisons).

People's experiences of transitions across services, particularly from children's services to adult services, were often negative due to a lack of knowledge on who, when and how to access support. In order to ensure a smooth handover when moving from one service to another it was highlighted that there is a need to understand the resources, roles and expectations from services and acknowledge that it takes time and experience to build relationships between the care team and the person and their family. Creating shared plans with people and families and opportunities for continuous open dialogue and mutual feedback was seen as key to ensure good transitions. It was also suggested that adult services should work more closely with paediatric services at an earlier stage before moving to the new service. Policy and practice needs to address the lack of social nursing care, support good signposting to services, facilitate cross boundary working (including integrating IT systems, e.g., KIS, ACP's, ReSPECT) and also ensure that out of hours services provide sufficient expertise and support for people and their family. Specialist services such as hospices have built up expertise by working with families and other services can benefit from sharing learnings and best practices.
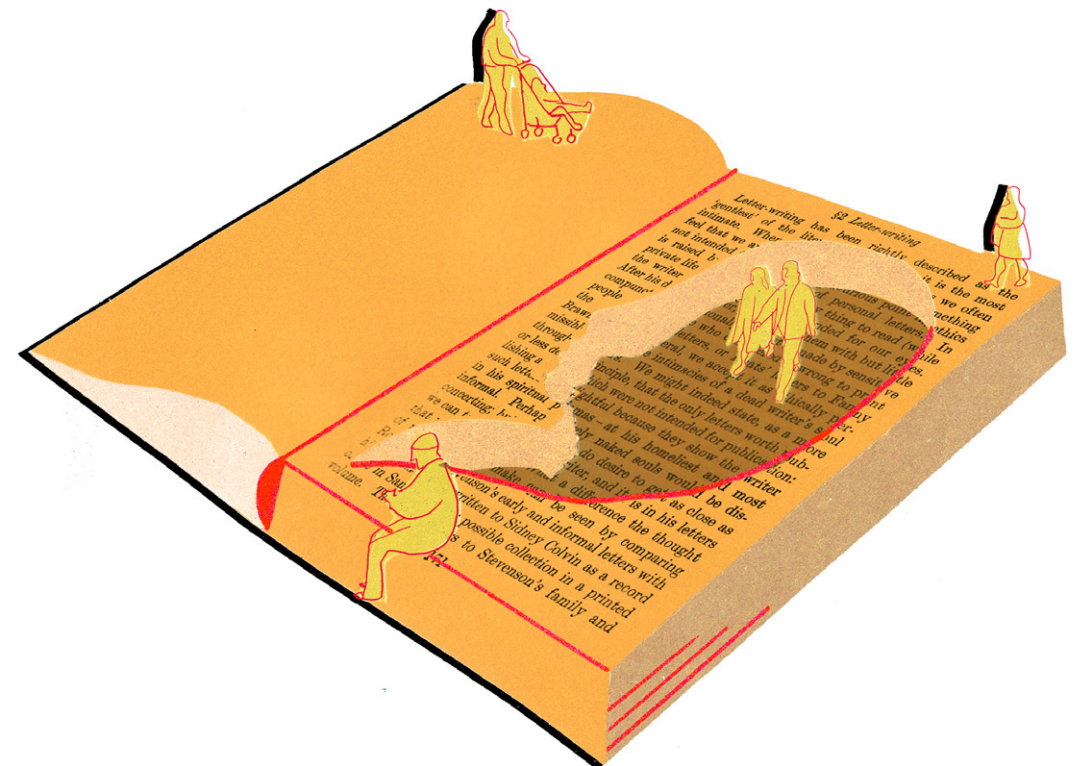
Creating Meaning and Legacy At the End of Life

People have stories they want to share and it is important to support them to build and leave behind a personal and social legacy. There is an opportunity to integrate legacy and memory making to good practice in order to support personhood (including digital legacy) and build courage at end of life and across the palliative care journey. There is a clear dichotomy of hope and fear that is experienced across the palliative care journey in terms of feelings of gratitude, aspiration, inspiration and selflessness but also of loss, grief, loneliness and uncertainty. Making memories and legacy can support people at the end of their lives to make the most of their time and accept new things that they have done or can still do. Involvement of the community and use of rituals was also highlighted as important to families during times of loss and bereavement.

Co-design Concepts

Welcome Box

The concept responding to the theme of 'point of diagnosis' aims to support the experience of diagnosis to move beyond a conversation to a process that supports any person receiving a life limiting diagnosis and their family. Diagnosis was recognised as a key 'point' which is important to get right in order to support the person's journey. The point of diagnosis is a transition where people need to recognise realities, respond psychologically, reach decisions, build resilience and retain hope. This means the clinicians language, tone and actions are very important but at the same time can also be a challenge to get right. There is a strong need to resonate with the person and understand their values and what is most important to them at that time.

Context and People

Introducing the term 'palliative care' can be challenging because it can lead to many interpretations. There is a need to address the understanding of palliative care across all groups (professionals, people, families and wider members of the public) to shift perceptions and raise awareness. This may involve considering alternative terms such as 'best supportive care' or may be a purposeful commitment to explain any terms used (including palliative care) in a positive way.
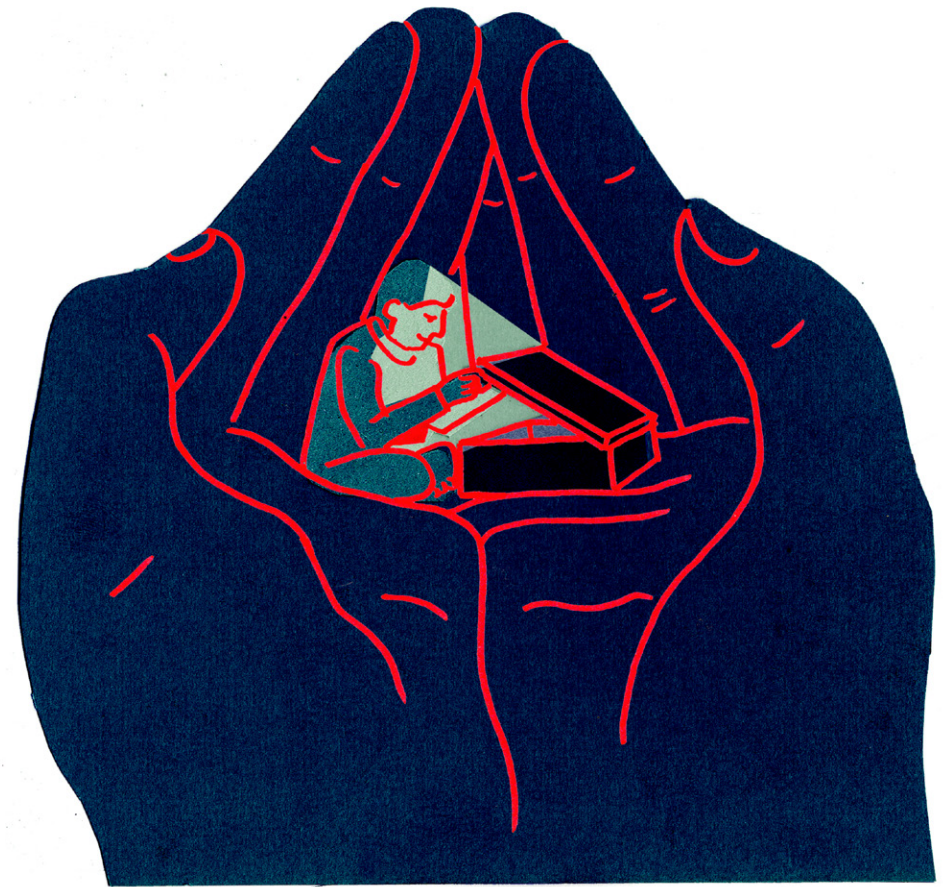
The challenges for health and social care professionals at this point of transition are linked to expectations and 'tone' of the system (e.g., risk adverse, burdens of governance knowledge and permissions). Consultants are often also not aware of what support is available and might offer something that may no longer exist. The consequences of making a choice that doesn't work highlighted the need to take a holistic view rather than focussing only on the individual. Additional pressures for paediatricians were also recognised when making difficult decisions around young people's care, including communicating when there is nothing more than can be done in terms of clinical care/treatment.

Assets

A number of key assets were recognised as important to the point of diagnosis such as shared decision making in practice and human qualities of kindness, being open and listening to what is important to the person. Specialist nurses, organisations who can provide support and tools that can help communication were also acknowledged as key assets. Existing models to promote conversations and offer guidance and pathways for assessments were also discussed such as the North West Model, GS Framework, Health Visiting Pathway, and NES brief and bereavement work. Dying matters and Death Cafes were also described as tools that could support public understanding and promotion.

Opportunities and Ideas

Several opportunities and ideas were shared to support transitions at the point of diagnosis including a 'midwife for death' and tailoring the dignity framework as a generic statement of care for the point of diagnosis. The tone of the conversation at the point of diagnosis is key including aspects of intention, care tone, behaviours and the environment within which the conversation happens. Enabling the right tone will support the rest of the journey and wider care. There is a need to shift from talking about professional 'distance' to professional 'nearness'. There is an opportunity to enhance shared decision making through communication care plans

in capturing what is important to the person and communicating what is available as well as showing the next steps. This led to the idea of creating a 'Welcome Box' to palliative care services that can support the person by welcoming them to a 'community' of information, resources and other people.

Scenario: bringing the 'Welcome Box' to life

The concept of a 'Welcome Box' would provide a practical and emotional source of support for the person and their family, providing access to information, pathways and networks that can support them in their journey and transition to palliative care. The box could support person-centred care by enabling people to appropriate support and resources at the time they need it through signposting.

The idea of the concept would be something that could evolve and grow with the person allowing them to personalise and choose the resources they would like to be included. The box could be both physical and digital to allow people to build up content and personalise through additional online resources. The 'core box' would contain a range of preliminary information and resources that would be determined by co-designing the box with people who have experienced diagnosis of a life limiting condition. Overall the concept of a 'Welcome Box' needs to be able to be tailored, accessible, age appropriate and easy to use/understand.

It is important that the box contains a balance of both fun and practical items to support the person and their family. This could include signposting to social opportunities and volunteer support, stories from other people who have experienced a life limiting diagnosis and prompts for questions to think about for future health and social care interactions and other key events that the person is likely to experience. Other ideas for content included a 'talking stick' which the person can use in consultations with clinicians, 'permission slips/ vouchers' which support people to have 'permission' e.g., permission to cry, and other resources such as health visitor packs and practical activities for people and families. In this way the box would contain resources that enable connectedness both practically and socially.

Through the practical and emotional resources the box would provide a space for legacy both in capturing things that are important to the person along their journey and also as a way to inform the development of future welcome boxes. Each box that is designed can inform the development of the next box based on the content people choose and the ideas that come from the way people interact with and use the concept. There could also be capacity for people to send on items to others through personal letters and stories, or recommendations of resources and networks. Similar to the Compassionate

Inverclyde box, items for the box may also be created/ gifted by community groups. This means that a whole range of different stakeholders can be engaged and involved through the box in terms of who can create materials and resources and how the box is shared and introduced to people. For example, volunteers, local artists/authors, people who have experience of palliative care, schools, interpreters and children can be involved.

Although the 'Welcome Box' can be a resource that is rolled out nationally, it is important that the boxes are created locally to ensure access to available resources and networks. There are a number of ways that the box could be received by the person, including during an outpatients appointment or post diagnostic visit, from the health and social care partnership, potentially from a social worker or following a similar route as Compassionate Inverclyde. It is important to consider the best way and the right person to deliver the boxes. Many of the resources already exist that could form the content of the boxes however, there are still governance considerations required and the option to explore the provision of boxes through sponsorship of companies or local businesses.

A final consideration is the need to explore the concept of 'welcome' in relation to how this term would be perceived and understood, and also consideration of people without families.

Realising the Concept

The overall vision for the concept is that it will support the point of diagnosis to change from a medical event to a process through which people are informed and connected ('welcomed') to a new community.

Short Term Actions:

· Co-designing the concept with those who the concept is intended for and other key stakeholders e.g., professionals, volunteers etc. The co-design

process will be informed through the learning from Compassionate Inverclyde. This will enable the content, aesthetic and process through which the concept is provided to people to be user-driven.

· Exploring the types of community support and assets that could play a role in the concept. This would be a national and place-based exploration in locality/partnership areas across Scotland to support what the concept would offer from a community perspective and how the community may play a role in providing the concept.

· Refining the concept through Care Opinion

Scotland to determine the impact and raise awareness to open involvement to new partners.

Long Term Actions

· Refinement and personalisation of the concept in order to include recommendations from people who have used the concept to inform the design of future iterations. This may include children/ young people sharing letters/images with their peers through the concept or adults forming peer support networks.

· Nationwide roll out of the concept after co-design testing and iteration. However, the concept would be dependent on the local resources available in different communities.

· Understanding how the concept could enable successful integration of health and social care through the contribution of health, social care, third sector and the community in providing content/tailoring the concept.

Conversations and Rituals

Lack of appropriate care options when going back from hospital to home is a barrier to supporting people to continue living at home. It makes for a difficult conversation as often discharging people from hospital and conversations around not continuing treatment although it might be in the best interest of the person, are negatively perceived as abandonment or lack of care. It emerged that entering 24 hrs care can be one of the most difficult transitions for an older person, and this discussion between an older person and a health professional or a carer is one of the most challenging conversations. For example, when a health professional says 'there is nothing more we can do' in terms of clinical treatment, it may be perceived that they are 'not going to do anything' for the person. The option of moving into a care home is often foreseen as an undesirable step due to various reasons such as widespread perception of care homes as 'places of dying', fear of moving away from family and community, and the high costs associated with them. A lack of appropriate training and the fear of using sensitive terminologies related to death and dying among some health professionals can also make these conversations challenging. Absence of support from family or complicated relationships can further make people feel vulnerable and isolated in these circumstances.
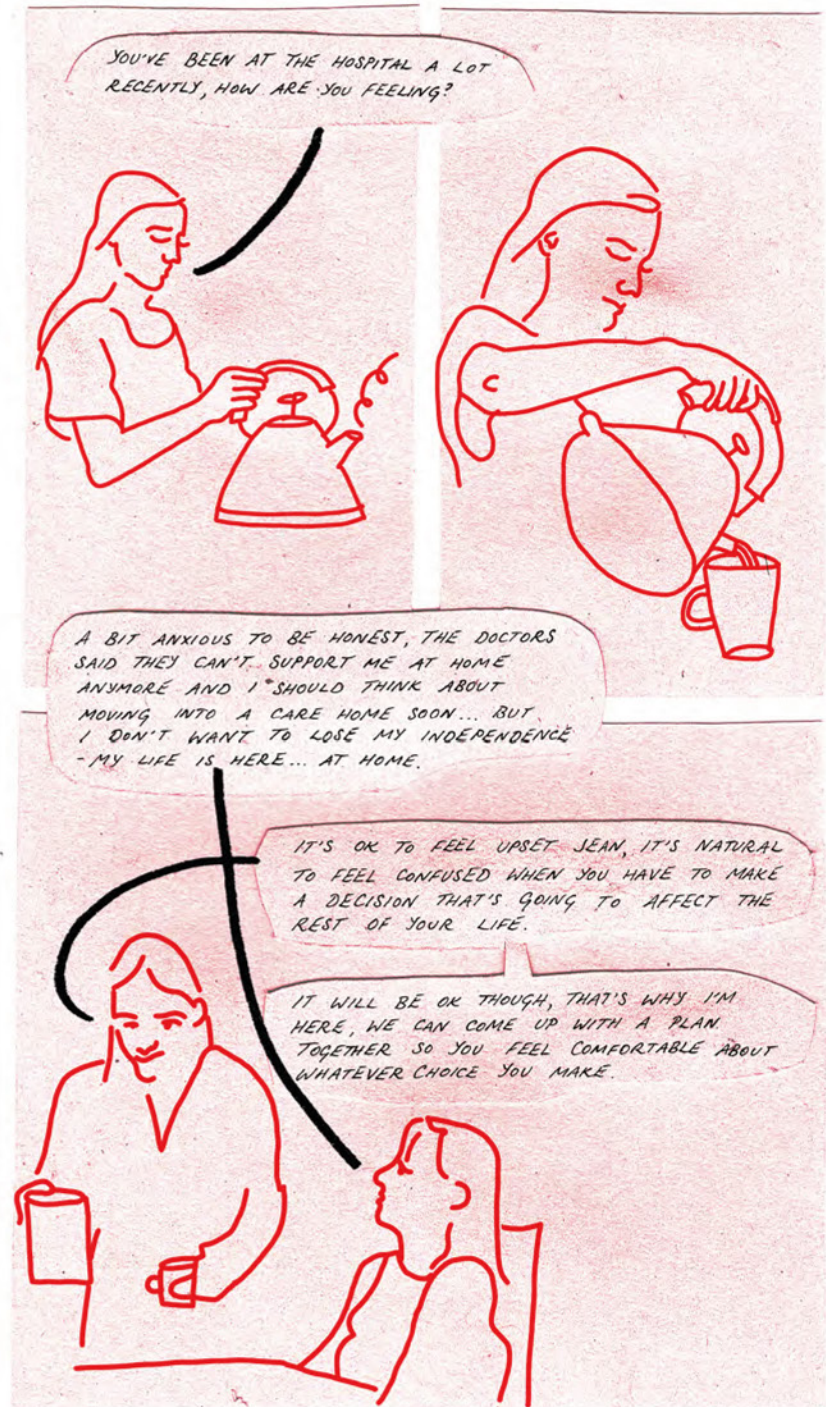
Context and People

Jean is 80 years old and lives alone at her home. She was diagnosed with dementia a few years ago, and has difficulties with reduced mobility and declining vision. Jean has a daughter and a son, both of whom live far away with their families, and are not involved in Jean's everyday care. Jean requires different types of care interventions about four times a day.

Jean has been in and out of hospital several times in the last six months and after the most recent admission to the hospital, the clinicians feel that Jean would need more routine palliative care. A few years ago when she was diagnosed with dementia, she was advised by her doctor to consider moving to a care home. However, Jean had expressed her will to continue living at home and her kids were supportive. Jean is feeling anxious about having to revisit the decision. Her kids have grown distant in the last few years and she finds it difficult to share her concerns with them, and does not know who to speak to.
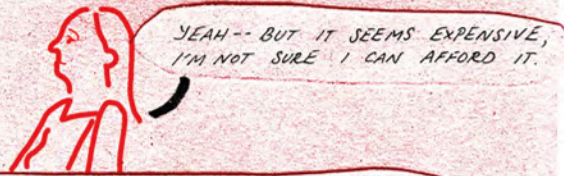
Changing The Story

In the future (2030) what if Tina, the community based transitions mentor visits Jean on her return from hospital?
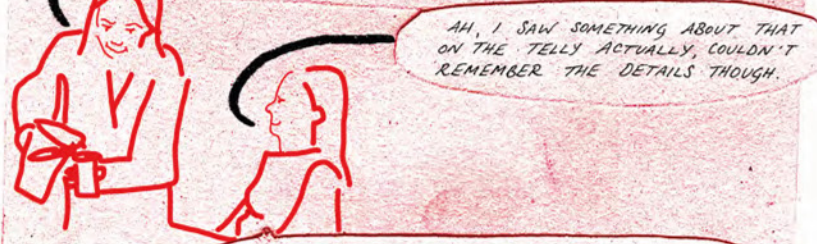
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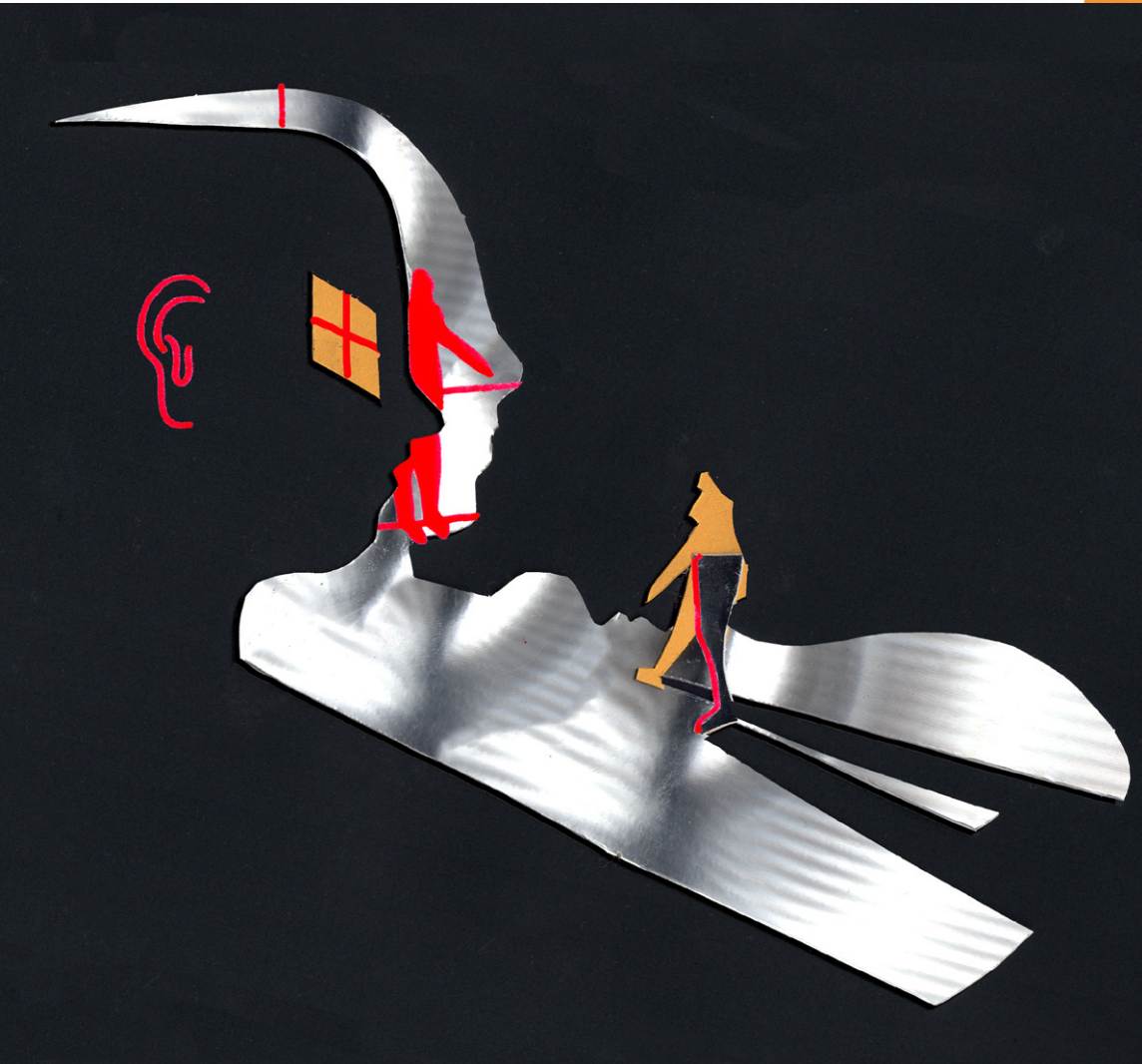
When someone is diagnosed with a life-shortening or life threatening condition they can be seen by others as different. They lose the identity they had, the identity they might want to have. This can be disempowering and stifle independence and an ability to adopt a positive attitude to their new

situation. On the other hand the person themselves may regard themselves as having a different identity as a result of the diagnosis e.g. unable to be the mother, wife, husband, brother, sister or friend they want to be.

This is also true for those caring for someone with a life-shortening condition. Becoming a carer is a change of identity and can happen to all ages of people including children.

It is therefore vital for professionals to be aware of this and seek to understand people and try to understand what they need. Professionals must recognise that this will change over time, or fluctuate backwards and forwards, and so requires to be re-visited regularly.

Young people are a very particular group. They are already going through transitions into adulthood which are not easy. To be given a life-shortening or life-threatening diagnosis only compounds this. They may not find it easy to share what they need.

Young carers are also a very particular group. They may have to cope with responsibilities far beyond their years and make decisions that are not usually expected of young people. However, they may want to do this. But there may be times they don't. It is therefore important to work alongside young people to find out their needs at different times.

Educating professionals in this concept is important and providing resources to help them do this is worthwhile. It is also important to educate the public because we know the value of people's own support networks and those of volunteers.

Context and People

The concept that has been created is the development of a mentorship programme where people who have experience of a life-threatening illness or caring for someone with a life-shortening or life-threatening condition can provide guidance for people with life-shortening or life-threatening conditions and/or their carers and/or the professionals supporting them. The mentors can be people with or without a health or social care background. This will enable the sharing of good practice.

Scenario

Mentorship will encourage best practice and support people not to focus on the illness but to establish what is important to the person with the life-shortening or life-threatening condition, their family and carers. There can be a reframing of mind-sets such as thinking about the language that is used e.g. not creating constant reminders of the illness. Family members and others often don't know what to say and do, and need guidance.

Thinking in a different way can fade and blur the line between care and 'life'. It is important to recognise that over protecting those with life-shortening or life-threatening conditions can rob them of experiences they could have.

Mentors will have experience of helpful practices and can sign post to appropriate services within the statutory and voluntary sector. Mentors can encourage bridges to be made between social and health care.

Hospice and palliative care for adults, young adults and children is a vital resource which can be provided both in hospice, at home and in hospital. It is important to address pre-assumptions about hospice and palliative care. Often people think it is only for end of life care. It should start much earlier than this and support people to live.

Anticipatory care planning can be used to support positive decision making and open conversations that focus on the individual and enable choices to be made around what matters to the person(s). This concentrates on wishes that are important to the person and their family; treatment plans; and place of care. Families will know who to contact if they are in need. It enables people to live life to full. The idea is to keep the focus on the person and their story. Storytelling has the power to connect people. A mentor can support others with ongoing ACP conversations.

Mentors can help people to build support networks and encourage peer support. This might be in the form of support groups for parents, peers, siblings or young people. Social media can also provide a good platform for support. It is important to educate people to know that it is okay to ask for help – both the care receiver and care giver.

Research can help us understand the lived experience of those with life-shortening and life threatening illness and their carers. However, people and in particular young people, don't always engage in research studies. Mentors can facilitate the required engagement.

It is also important to challenge the community around perceptions of the needs of people with life-shortening or life-threatening conditions. Mentors can support and help others do this.

Resources required for the development programme:

- Project plan to enable this.

- Use of improvement methodology to develop the programme.

- Feasibility study to identify who might be mentors.

- Support for mentors.

- Awareness raising of the mentorship development programme.

- Use of storytelling to understand the past and improve experiences for people, and also to demonstrate the value of the programme interventions about four times a day.

Outcome

Success will include the following:

- People will say that they feel they have more control over their life.

- ACP wishes will be realised.

- Family members will learn, develop and contribute to their loved ones care.

- Wider family will assume a helpful role.

- Person and /or family can identify a key worker that suits them.

- Independence will be facilitated.

- Person(s) not being heard will be heard through storytelling and research.

Community Compass

Research suggests that people requiring palliative care and their family experience several transitions; for example as a result of the diagnosis of a life limiting condition, change in identity, etc. Although professional support is available to them, the focus of that support can be on clinical or (physical) caring matters. Volunteers and local communities could play a crucial role in providing compassionate social and emotional support to those receiving palliative care, as well as their family. However, more thinking is required to understand how communities and volunteers can be involved in creating compassionate communities of care.

Context and people

The concept that has been developed is a Virtual Box or Hub of resources that acts as a compass to support individuals and communities to navigate palliative and end of life care. The idea is that by providing information about how other communities have developed a Compassionate Community Model and by providing a wide range of information about sources of help and support, the hub/box will inspire and enable individuals, volunteers and communities to develop supportive networks around people with PEOLC needs.

EDUCATION

LEISURE

PWPC

COMPASSIONATE COMMUNITIES

FINANCES

CARERS + FAMILIES

COMMUNITY COMPASS

FRIENDS + COMMUNITY

WHAT ALREADY EXISTS?

SPACES + CONTEXT
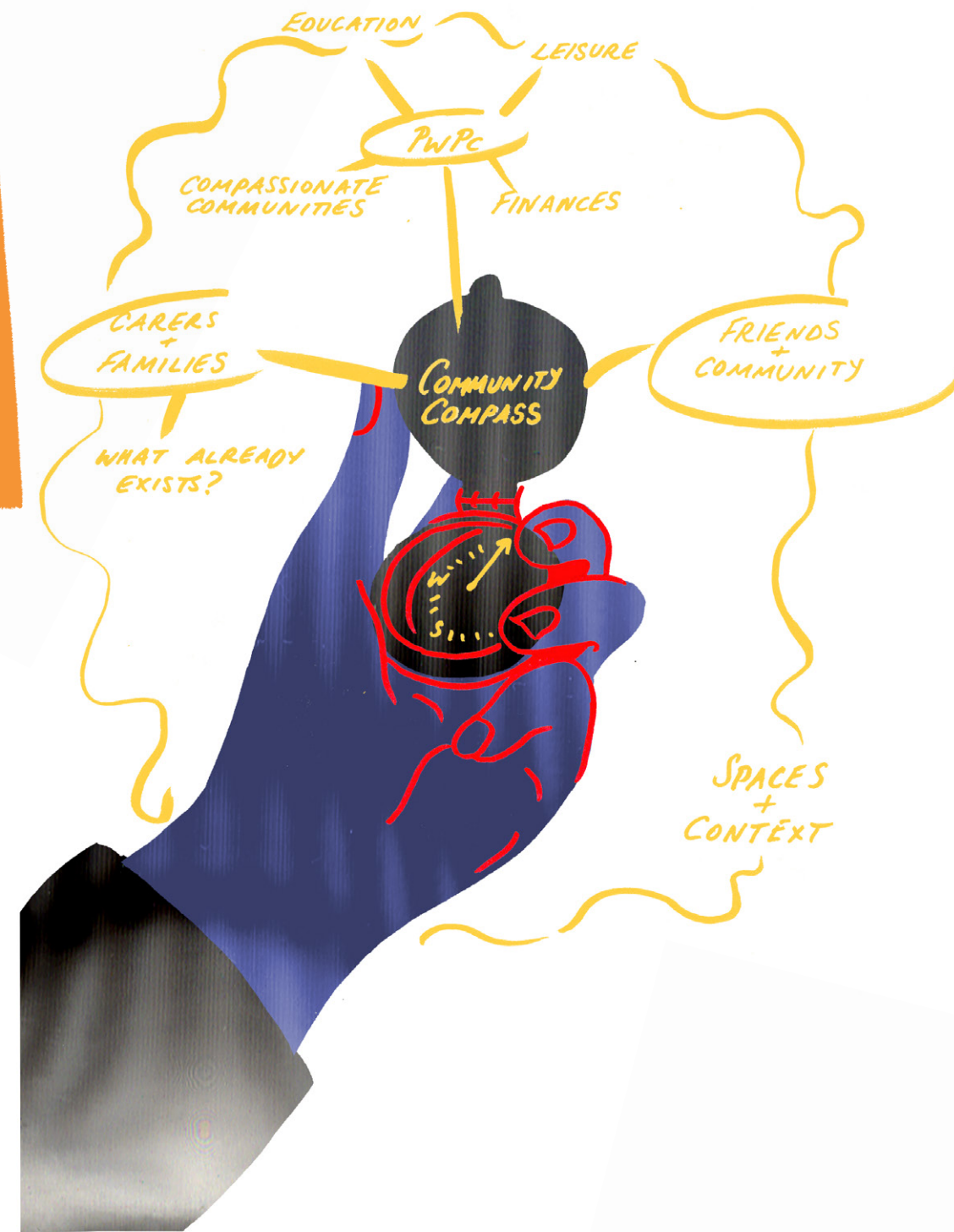
Scenario

The hub will help improve awareness and understanding of palliative and end of life care across the age range. It will provide links to sources of support in communities. It will be interactive. It will bring together in one place existing information and resources for individuals and communities along with space for them to add their own. The hub will support volunteers and local communities in providing holistic support (social, emotional and practical) to people of all ages with PEOLC needs and those who care for them. During the provision of resources we will be mindful that within a community there are many communities around the person with PEOLC needs. Resources will therefore be specific to the spaces and contexts of individuals. For example resources will include information about, and electronic links to, the principles of good palliative care transitions, existing community palliative care projects such as Compassionate Inverclyde, Scottish Compassionate Communities Network, Compassionate Neighbours, Changing places toilets, Facebook Groups, grief and bereavement comic, links to bereavement resources and organisations. All partner resources and links will be included. The virtual box or hub will include story telling and legacy through links to video clips of people talking about their experiences. Examples of helpful links include Bill United Milford Care's animation of a compassionate community through Bill's story (https://www.youtube.com/watch?v=mqYmTTY-3gs),

Lucy Watts YouTube (https://www.youtube.com/watch?v=x2XEkEgJ1c8), Independent Living Dundee and Angus. https://ilda.scot/

Within the hub resources will be categorised for easy access – care and support, education, employment and financial.

It is envisaged that the virtual box/hub will be available to all through multiple organisations websites For example: Taypeolc, SUII, TCELT, Hospice umbrella organisations, GPs, community umbrella organisations, volunteer centres, local authorities, all SUII project partners.

Badging

A further aspect of the Community Compass is the possibility of badging communities (similar to Dementia Friendly) as "Living well at end of life compassionate neighbourhoods". One of the key aims of badging would be to create and recognise a sustainable neighbourhood model that meets the needs of that particular community.

Resources required

- Mapping exercise of resources will need to be undertaken.

- Gaps identified.

- Skill set for developing the hub.

- Parameters/ steps for badging.

- Videoing and editing.

- Organising TedX talks.

Outcome

The outcome of a Virtual Box/Hub would be smoother and better informed transitions through better understanding PEOLC, and signposting to resources and support available. It would enable individuals and organisations to contribute information to the hub thus not taking away control. It would also offer value and impact for all stakeholders with information collated and made available in one place enabling people to find information on, and access, the support they may need. A sense of belonging will be created through encouraging people to develop community support and new resources
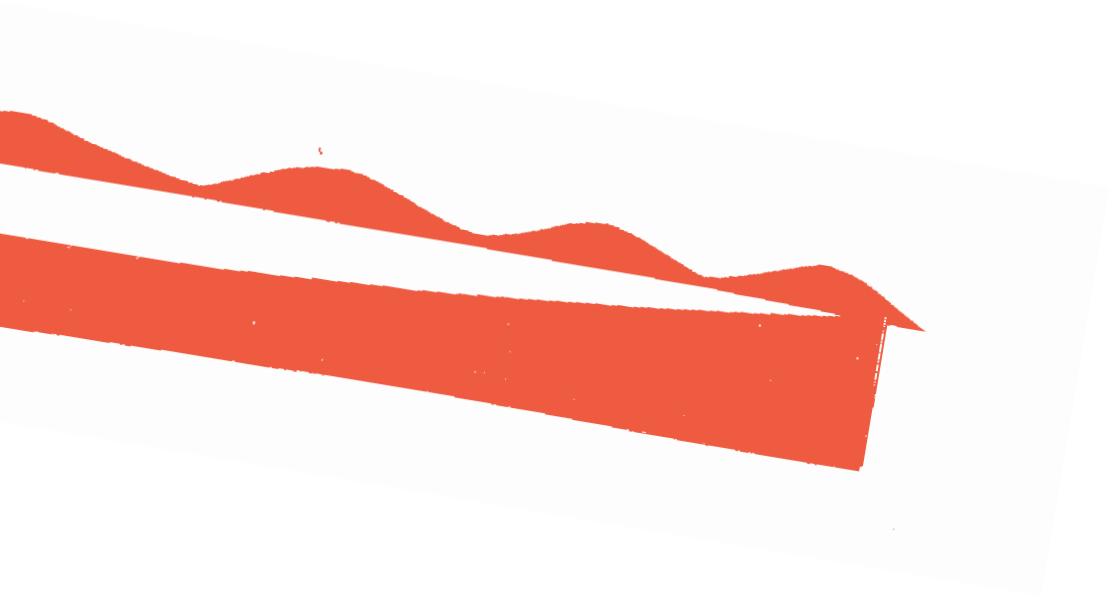
Inclusivity: ==Building Voices== and Aspirations

The concept responding to the theme of 'inclusivity' emphasises a strand within training, supervision and modes of practice that helps practitioners to determine what people need now and are likely to need in the future. This involves being aware of what gets in the way of our capacity to be aware and respond to a diverse range of needs and make palliative care inclusive and accessible to all.

Context and People

A key challenge in achieving inclusivity in palliative care transitions is that nobody really knows what lies ahead. The importance of empathy and understanding along the journey is key as well as being and feeling heard. In particular, there is a need to hear unheard voices who find it hard to engage such as those in prisons or who are homeless, as well as hearing the whole family/carers voices. People can often feel isolated and withdrawn, particularly carers. Practical challenges such as money and travel can also impact palliative care transitions and there is an urgent need to address the way in which poverty impacts pathways of care.
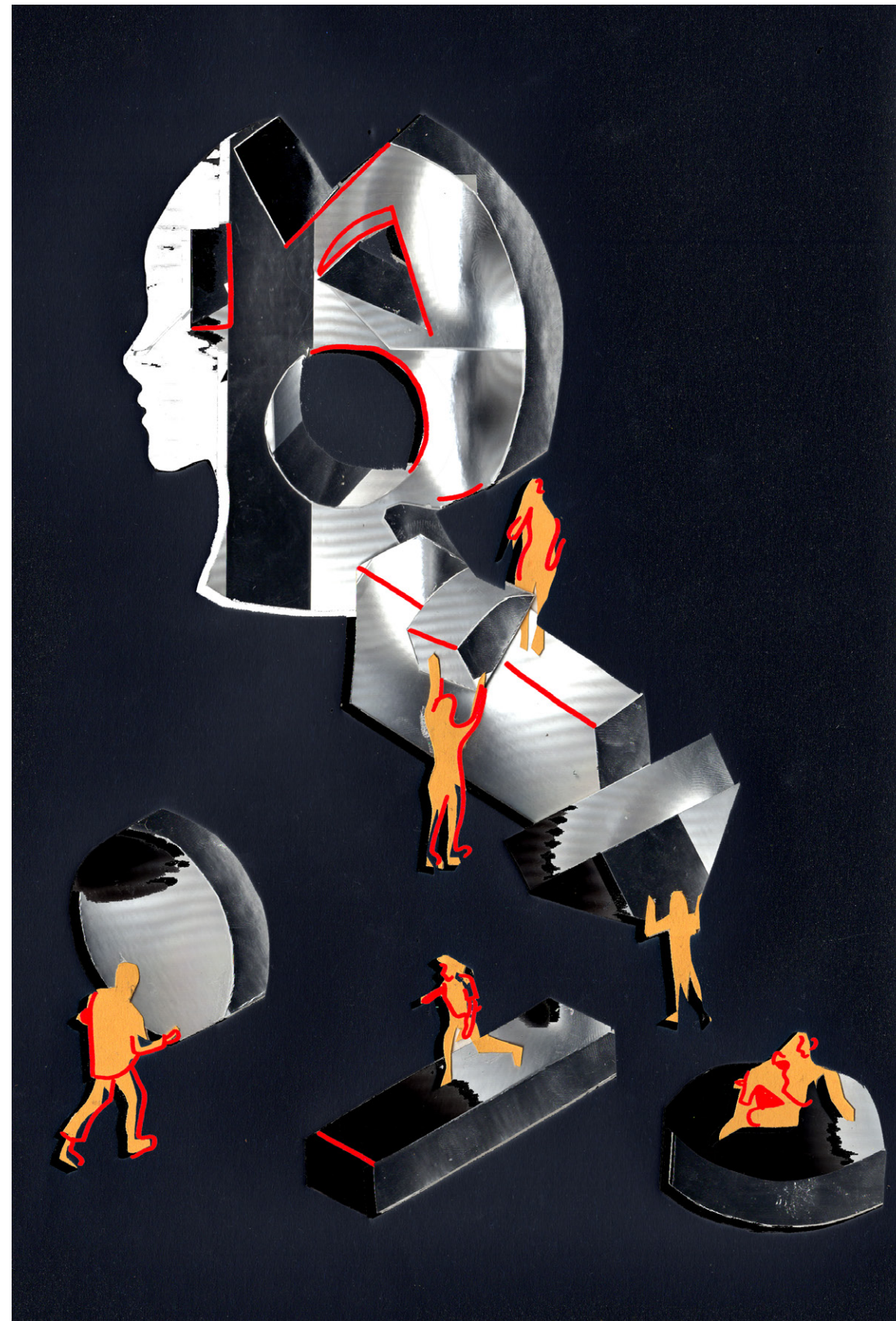
The cycles of crisis and stability can be disruptive to transitions. Connecting support around each person and ensuring services are not disconnected can help to ensure that people receive the care and support that is needed at the time. There is also a need to support people to realise their potential, provide hope and support positive changes when experiencing palliative care transitions.

Scenario

Enabling people to be prepared, think ahead through encouraging early discussions and considering the role of advocacy for those whose needs are in tension with other needs will be key. Bringing plans together through family group decision making could also be explored. Helping to link people up with existing services and resources can help people to know what is 'out there' and available to them. Developing a 'Lead professional' could help in listening to people and linking them up with the appropriate services.

Supporting coordination of plans when needed could be complemented by exploring a tool or format that captures needs and feelings (e.g., PAMIS's digital passport). Exploring self-directed support and ways of ensuring plans are personalised for all, especially for those who are non-verbal.

The opportunity to engage people in education and life long learning about dying could also offer opportunities to those who are isolated by their conditions or by caring. Opportunities for post qualifying education and support for those providing palliative care could also be explored.

Finally, there is an opportunity to develop shared language and principles in palliative care and supporting learning, development of values and positive attitudes through training/supervision and reflecting on practice and experiences. In addition, developing and enhancing training in communication, reflection and empathy are all key to supporting inclusivity in palliative care transitions.

Assets

Every person and every story is an asset and there is a need to build on the strengths that exist in every carer, family and community. Opportunities can arise when the expertise and story of each person and each family is listened to. It was also highlighted that siblings should be included in support planning not only in recognition of their own assets but also in the needs that they will have.

The models that exist and are used in the context of children, e.g. concepts of wellbeing offer an asset based model for palliative care transitions. Building on existing assets and resources such as these along with anticipatory care planning, house of care model, current service structures is important. Seeing the opportunity to learn and reflect from experiences for both families and professionals is also a key asset.

The compassion and support of volunteers and the community also offers an asset for achieving inclusivity and building voices and aspirations. Dying is a part of community life. Appreciating cultural differences offers learning opportunities and are a key asset that can be realised.

Although specialist knowledge is recognised as a key asset there is a need to have someone besides the family who understands the whole person and has an overview of the whole picture.

Additional Resources

Short Term:

· Promote a message that palliative care is a journey for the person, family and carers within a community.

· Coordination of care supported by link working and key people.

Long Term:

· Greater understanding that palliative care can have a positive impact on the person and their community.

· Building partnerships around the person and their community.

Outcomes

The concept will support inclusivity by:

· Using plain language to explore what will help the person is known and describe what is known or not known about the condition and choices.

· Acknowledging feelings and showing care through winding emotional journeys.

· Acting more practically or without any practical intervention, by just listening.

· Noticing significant changes and being curious about what this means for care and coping.

· Preparing for anticipated needs and responding calmly to unpredictable scenarios.

· Working towards co-ordinated professional action when appropriate.

· Supporting family leadership of plans around a person when appropriate.

· Linking people with information or access to sources of information that would enable them to connect with services themselves.

· Reaching out to those who are locked in or locked out of services, are isolated or self-isolating.

· Recognising and respecting the strengths of those who are bearing the strain and yet have their own needs.

· Realising that a person facing life limiting conditions may have new possibilities in relationship, skill, meaning and enjoyment for some as abilities and relationships change.

Quality of Life at the Centre of Quality of Care

Health and social care, as well as voluntary and community care services, are often challenged to show how the care they deliver is efficient, effective and of high quality. However, many of the metrics which are used to indicate efficiency, effectiveness and quality face towards the services themselves rather than those people whose lives are entwined with care services. Take for example 'efficiency' which is often measured by how many people received services within a stipulated time and place (and not whether those services made a positive difference to their lives). Is the service effective ('effectiveness') is often measured by how many of the stipulated population receive the service. And the question of quality is often translated into organisational processes and staff practices concerning 'is the service doing what it says on the tin' and 'are the staff following correct procedure'. Instead of a focus on services and how they operate, surely promoting the best possible quality of life should reside at the centre of care. This vision of the promotion of quality of life through quality of care was explored further in this concept.

Caring for Quality of Life

What if quality of care was focused on quality of life for people experiencing the medical, social and psychological transitions that constitute living with a life limiting condition; what would 'caring through services' look like?

Four key concepts were felt necessary to underpin such a proposition:

(**1**) Family centred and not (just) 'person centred' care in recognition that living with a life limiting illness impacts on all members of the family whose needs should be taken into account when care is planned and delivered. This should also continue to support families with the practical and emotional aftermath following death. When planning immediate and future care, consideration of how the person/family can retain control (where possible) and maintain a level of independence, or more accurately, inter-dependence, is important. As well, refocusing away from medical and service needs to the realities of daily living and everyday enjoyments is critical to enable the person to retain a sense of identity and personhood. It is the person who has the illness-not the other way around.

(**2**)_Provision of safe spaces (physical and social/personal) to explore both positive and negative emotions. Community cafes, day care, hospital care, hospice and care home as well as respite care are all implicated here. Seeing familiar (staff) faces encourages the development of trust which in turn enables difficult, but compassionate conversations to ensue. One to one opportunities for discussion are essential for the person at the centre of PEOLC.

(**3**) Embedding compassion across all aspects of care. Compassionate commissioning which explores person, family and service requirements to provide more tailored, wrap around services to provide support for ALL involved. This would need full consideration not just of care of the person and family during life, but also commissioning of care after death in bereavement support which recognises that everyone grieves differently. Finally, compassionate commissioning should integrate care across different services and involve the person and their families rather than operating in a more piecemeal (and cost oriented) fashion when funding services.

Development of compassionate communities which might include:

· Supportive friends and neighbours (requiring that ability to talk about illness, death and dying in comfortable shared conversations).

· Widely acknowledged 'Death Cafes' as settings for social but also support needs, building awareness of the normality of death and dying in everyday life.

· Adaptations to community facilities to enable the inclusion of people in PEOLC eg. Walking groups with adapted routes.

· A focus on dignity in everyday settings such as hairdressers, the provision of easily accessible, available and spiritually and culturally sensitive care.

Development of compassionate cultures within service organisations, across communities and within individuals. Examples of compassionate cultures of care include consultants visiting people in their own homes, night care services when needed (when anxieties are heightened), familiar faces, hospital safe rooms, and continuing support after death.

(**4**) Education to promote compassionate conversations, compassionate plans and compassionate sharing between person, family and care providers. Such education needs to be offered

to both staff and patients, to family members and informal carers, to young and old alike. In particular, training of general health and social care staff, care home aides in the meaning of palliative care should promote more positive experiences towards the end of life.

Transitions, which transitions?

Key transitions identified during the workshops were:

· Receiving a diagnosis.

· Deterioration in the illness.

· Intensification of symptoms.

· Treatment failures.

· Young people moving into adult services.

· Changes in family circumstances, support & dynamics.

· Loss of connections and social networks (eg. when leaving work due to illness).

· Identity transitions: Becoming 'the one who is dying' or becoming a carer.

Enhancing quality of life through such transitions requires that the person and their families know:

· Who can provide support.

· When to access support.

· Which sorts of supports are available.

· Where they can go to.

· What is likely to happen in the future.

Having a key person/organisation to contact, and receiving quick responses from that person/organisation was viewed as good practice. Ensuring processes are in place for shared decision making is key to quality transitions and encouragement and support to live life to the fullest. People who are dying can have aspirations for their future and for the future of their families. Recognising and enabling this should be as much part of service delivery as the medical and clinical aspects of care. People in PEOLC can benefit as much as the rest of us from having new opportunities opening in front of them.

Transitions, Development and Reflection

Lying at the heart of these propositions is the knowledge that if quality care is to intersect positively with and heighten quality of life, then there needs to be constant vigilance to recognise, make visible and attend to people and families at transitions points in both their care journey and their experience of the their illness. If transitions in PEOL experiences and care are to be taken into account in care provision, then structured opportunities for reflection on care practices are needed. These could be organised around such questions as:

· How can 'assessments of need' better identify and accommodate transitions involved both for the person and for their family?

· What lessons can be learned from experiences of providing care to provide input to the development of services?

· How were the more ambiguous elements of care handled such as compassion, dignity and love?

Future of Quality of Life through Quality of Care

Given the learnings realised through the workshops, some key ways forward to developing Quality of Life through Quality of Care lies in co-design of future care, by:

· Identifying which experiential, academic and sectoral knowledges and expertise should be around the table when developing such services.

· Agreeing a shared vision and joint agenda for change.

· Agreeing responsibilities and roles for achieving change.

· Ensuring issues of control and inter-dependence (eg in shared decision-making) are understood and actioned.

· Re-focusing on the person in the family in more holistic understanding of care needs, especially during transitions.

· Changing the metrics of success to those centred on the quality of life of the person In PEOLC and their families.

· Changing current clinically oriented cultures of care to compassionate cultures of care which include clinical issues and compassionate commissioning.

· Provision of education to promulgate cultural change and reflection for future learning.

· Developing compassionate communities where talk of death and dying is normalised, dignity is preserved and inclusion is a cornerstone of enjoying life to the fullest.

Outcomes

Future Priorities: Research, Policy and Practice

A set of priorities for research, policy and practice have emerged which give direction for future transitions as well as wider palliative care in Scotland.

Research Priorities

The findings across the programme have identified a need to reframe the challenge of transitions to see transitions as something that is positive, rather than focussing on the negative aspects of transitions. Research needs to be directed towards understanding and collecting experiences of positive transitions.
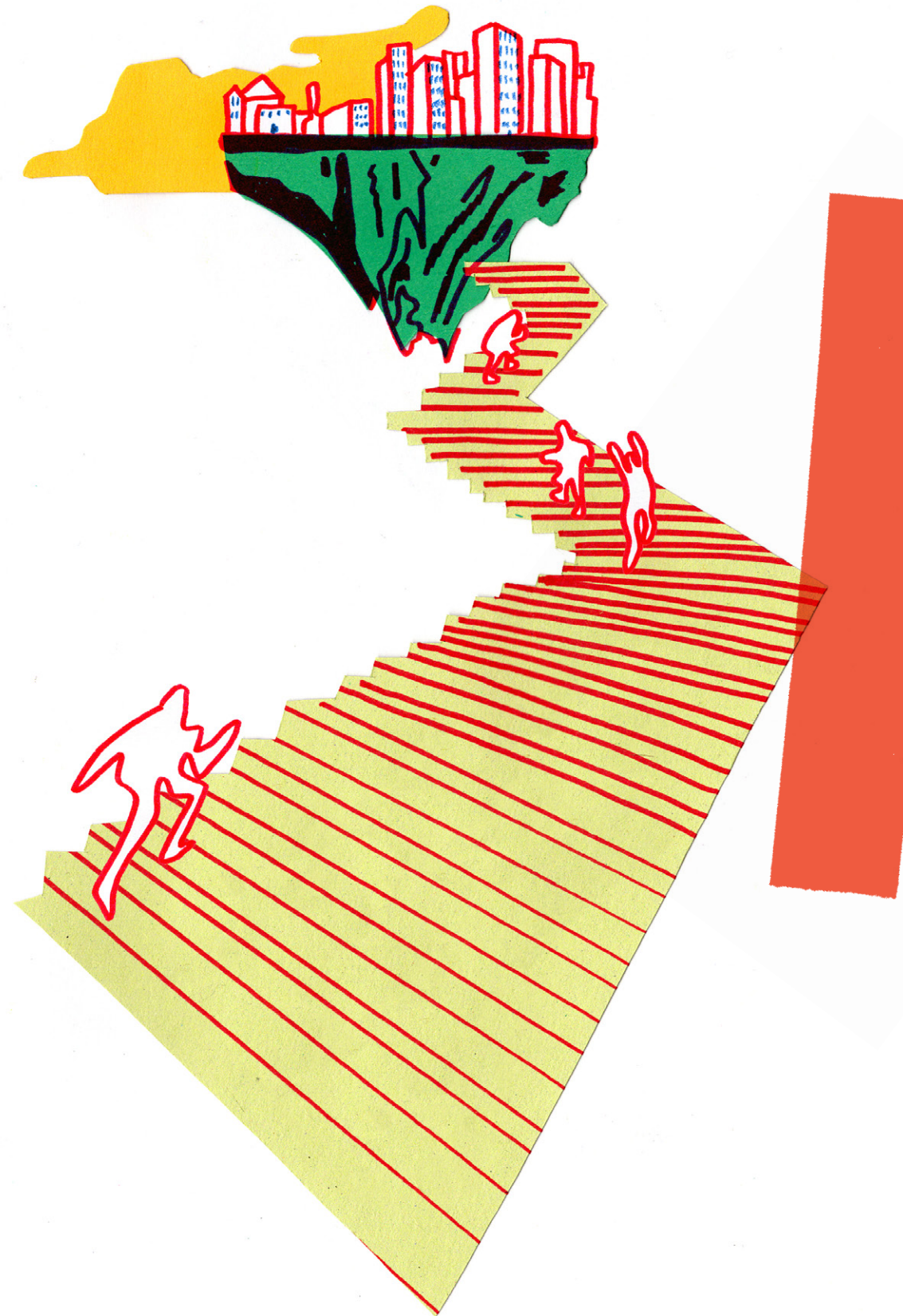
Emerging areas for future research

· To undertake an extensive review of international palliative care models, including children and adult hospices, to determine characteristics of optimum palliative care provision and enabling conditions for positive transitions. This should also focus on the optimum model for young adults whose needs are not fully catered for by children or adult hospices, and supporting positive transition from children to adult hospice.

· To investigate the effectiveness of technology in supporting good end of life.

· To explore the Multiple and Multi–Dimensional Transitions of people at the end of life and significant others, including changing identities and roles, and any trauma associated with diagnosis or care.

· To understand the role and impact of volunteers and the local community in the provision of palliative care and supporting positive transitions.

· To assess the role of dignity therapy in ensuring good life and death, and its relationship with similar interventions.

· Use and create transformative research methods that really 'listens' to the voice of people with lived experiences, such as people at the end of life with complex needs, families and professionals.

· To understand the culture and psychology of death, and identify effective ways of discussing death and dying in a safe environment, including exploring the role of schools in creating a culture that can discuss death and dying without any stigma or trauma.

· Integrating legacy and memory making to good practice – personhood.

Key recommendations for future research

· Understanding where policy is enabling in palliative care transitions.

· Understanding the role of community in providing support in palliative care.

· Overcoming ethical barriers in palliative care research.

· Translating research into practice and implementation, focusing on best practice and culture.

Policy Priorities:
Key learnings from the programme
and links to current policy.

The findings across the programme highlight the importance of narratives and stories in both informing and underpinning policy as well as communicating and translating experiences .

Emerging focus areas
and ideas for future policy

· Developing policy around death in care homes.

· Shifting the culture around medical shared decision making and preparing professionals to share power.

· Learning from other cultures.

· Learning and creating new ways to influence policy and sustaining engagement with policy.

· Developing a proposal around the role of design in policy.

· Ensuring multiple voices inform policy.

Key recommendations
for future policy

· Developing a charter for end of life which is reviewed every 5 years.

· Creating open and transparent language of policy, visual and jargon free.

· Commissioning based on identity – impact on person-led policy making.

· Stories underpinning policy to provide context and empower people to adapt/translate to practice.

· Realistic policy – 'dynamic risk assessment'.

Practice Priorities:
Key learnings from the programme
and links to current practice.

The findings across the programme highlight the need to provide appropriate and accessible transition services for all. There is a need to instil an ethos of doing 'with' rather than 'to' or 'for'. Linking to current health and social care integration, there is need to look at integration in its broadest sense and have opportunities to breakdown silos, working across boundaries to bring everyone involved in the care of a person and their family together to understand roles and skills.

**Emerging focus areas
and ideas for embedding
findings in future practice**

· Families to be involved in caring alongside professionals, and enabling greater trust in communities from professionals.

· 'Humanising' services rather than only 'person-centred'.

· Supporting health professionals through 'permission to create', e.g. new job roles/skills.

· Transitioning from hospital to home to take home some of the experiences.

· How do we link up pockets of good practice across and give opportunities to adopt in other areas whilst making bespoke?

· More opportunities for holistic, whole team reflection to identify emotional intelligence and recognising broader elements beyond 'professionalism'.

· Using lived experience stories to provide a basis for care (including lived experiences of professionals), and sharing stories in a format with health and social care professionals that would enable them provide person-centre care.

· Permission to care – moving from 'performing care' to 'caring'.

· Revisiting what practice means and who it involves.

**Key recommendations
for future practice**

· Facilitating conversations around death and dying across education curriculum.

· Supporting professionals to have conversations around death and dying (particularly with children and young people).

· Supporting people to tell their story and create legacy building on practice from dementia and PAMIS (digital passport).

· Removing labels and using plain language.

Future Proposals

Exploring alternative formats for sharing stories and communicating experiences

The need to engage the public and address the wider challenge of raising awareness of palliative care and promoting discussions around death and dying have led to an exploration of ways to support public understanding and increase engagement with these topics. The use of creative storytelling in the 'flurries' provided the participants with a platform to share their experience and also explored the way in which this approach allowed that experience to be translated into a visual format that allowed more people to engage with the stories during the co-design.

Discussions about end-of-life and palliative care can be very emotive for people with a life limiting condition, their families, professionals working with them and their community. It is important that children, young people and adults are able to have a voice about their experience of living with life limiting conditions and how it impacts them. Similarly, it is crucial to hear the narratives of those involved in their care. Although this voice is powerful, in wider research it is hidden in a narrative that is written and interpreted by a researcher. It can perhaps be made stronger if expressed in people's own voices through creative forms, both oral and visual.

Building on the success of the Fibromyalgia and Us comic (Jindal-Snape et al, 2017), future work in this area could develop a comic which will make these voices visible. The comic could include stories of people living with life limiting conditions and their family, and professionals working with them. The development of the comic can be scoped based on data from previous research to inform the types of narratives to focus on and developed through co-designing with people with lived experience. The format of a comic can allow these experiences to be relatable to others in similar scenarios as well as generate awareness of palliative and end of life care among wider audiences. Through adopting an open access format, the comic can be disseminated through platforms and organisations that have a wider reach to the public.

Another proposal is to have a stand up comedy event on death and dying. People with lived experience and their families could be invited to participate by actively sharing their experience or attending to hear the experiences of others. Events can be organised in the form of 3-4 hour workshops in line with the 'Bright Club' format. Participants who volunteer to take part and share their experience can be supported in developing skills in stand up comedy. These events can be structured according to the needs of people e.g., shorter events over a longer period.

Programme Reflections

Reflections on the programme and the individual programme activities were sought from seminar and workshop participants and members of the programme team. Participants were invited to complete feedback sheets on the seminar and workshop and were also invited to share their experience of participating through 'talking head' videos. Members of the programme team shared their reflections of the programme during one of the collaborative analysis sessions through open questions related to the design of the programme. The following themes emerged:

Breadth and depth of engagement

The range and diversity of participation in the programme, which included academics, practitioners, service managers, policy makers, carers, volunteers and people with lived experience was seen as a key success. This was highlighted as beneficial for developing a cross sectoral understanding of key issues and cross disciplinary learning. The richness and depth of engagement with those participating in the workshops through interactive sessions and during interviews was valued and it was highlighted that the diversity of voices led to richer conversations and reflections. The lived experience stories were felt to have captured genuine experiences of people receiving palliative and end of life care.

Ethos of participation

Participants and the programme team highlighted that the engagements set a welcoming tone and all contributions were visibly valued and appreciated. Everyone involved, participants at the events and the programme team, felt safe and enabled to bring forward their own perspective. They felt that the design of the programme fostered open and trusting relationships, with one member highlighting a "most refreshing absence of concern for status, ego, political positioning". The programme team also found the collaborative nature of workshops for analysis and synthesis of information gathered from the engagements and seminars useful.

Use of visual tools

It was noted that the design of the engagements in the workshops was imaginative and sparked many creative ideas. It was felt that the use of visual tools was "inspiring" and shaped the discussions in a way that people could hold them, personalise them and evolve them, through

open discussion and interpretation of difficult experiences. The nature of the metaphors used were highlighted as being gentle, allowing a safe structure around sharing of some deep personal experiences and thoughts despite touching on sensitive areas of living with and facing transitions related to palliative care.

New perspectives on Transitions

One of the members reflected that a key learning (and surprise) for them was the similarity of transition needs and challenges at both ends of the age spectrum. Working with people across different ages and stages delivering and experiencing palliative care highlighted that a holistic view of people's needs is essential as people are so much more than the sum of their medical conditions.

Lessons learned and scope for improvement

There is a need to ensure that the outcomes of the process can be valuable to those who did not actively participate in the workshop and seminars. Key to this is ensuring that the outcomes can be translated and communicated in a way that captures many of the positive elements described above. The connection between the images and

metaphors used in the programme and the potential use of these in the wider palliative care community and context also requires consideration. Translating and communicating the value of the programme methodology and process to inform future developments in palliative care will also be important for further work in this area.

Appendix

A digital appendix of the tools and visual outputs created as part of the programme are available online:

www.futurehealthandwellbeing.org/
future-transitions-in-palliative-care

Visual Outputs:

· Stories of transitions.

· Lived experiences of transitions map.

· Co-design briefs.

· Conversations and rituals comic.

Videos:

· Creative Seminar

· Co-design workshop

Acknowledgements:

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