HOSPICE AND PALLIATIVE CARE SOCIAL WORKERS GROUP

Social work, grief and Covid 19

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Social work, grief and Covid 19

- Context/opening remarks
- Social work as profession – our contribution
- Grief, loss and bereavement – what do we know?
- The pandemic as challenge and opportunity
- Self-care

Social work, grief and Covid 19

- Unprecedented situation on a global scale, with international, national, social, economic, personal and organisational challenges on a scale hitherto unknown
- Responding as a discipline within society and within organisations struggling with public health regulation and delivering care with uncertainty as the only constant at times as covid has challenged the way health care is delivered before and after death and into bereavement
- On a personal level, our basic needs, such as safety, security, income and social contact are threatened and disrupted, leaving many of us feeling helpless, fearful and anxious (Tavistock, 2020)

Social work, grief and Covid 19

- Managing risk in a new way for clients, colleagues and organisations
- Managing our own health needs and concerns and managing the needs of our own families, and of each generation. Generates fears and anxieties of a kind or of a level that is not usual
- Reflective practice within supervision and within teams has never been so important as we need support, supervision, connectedness, empathy and information

Social work, grief and Covid 19

- Self-care – pacing ourselves
- Break the task down into manageable pieces and set boundaries
- Flexible practices are now the 'norm' and crisis intervention strategies come to the fore
- Bring core social work values and principles to the fore – what is my job? And how to do it, albeit in a different way. Avoid role definition by others
- Be visible in your agency……. Reach out.

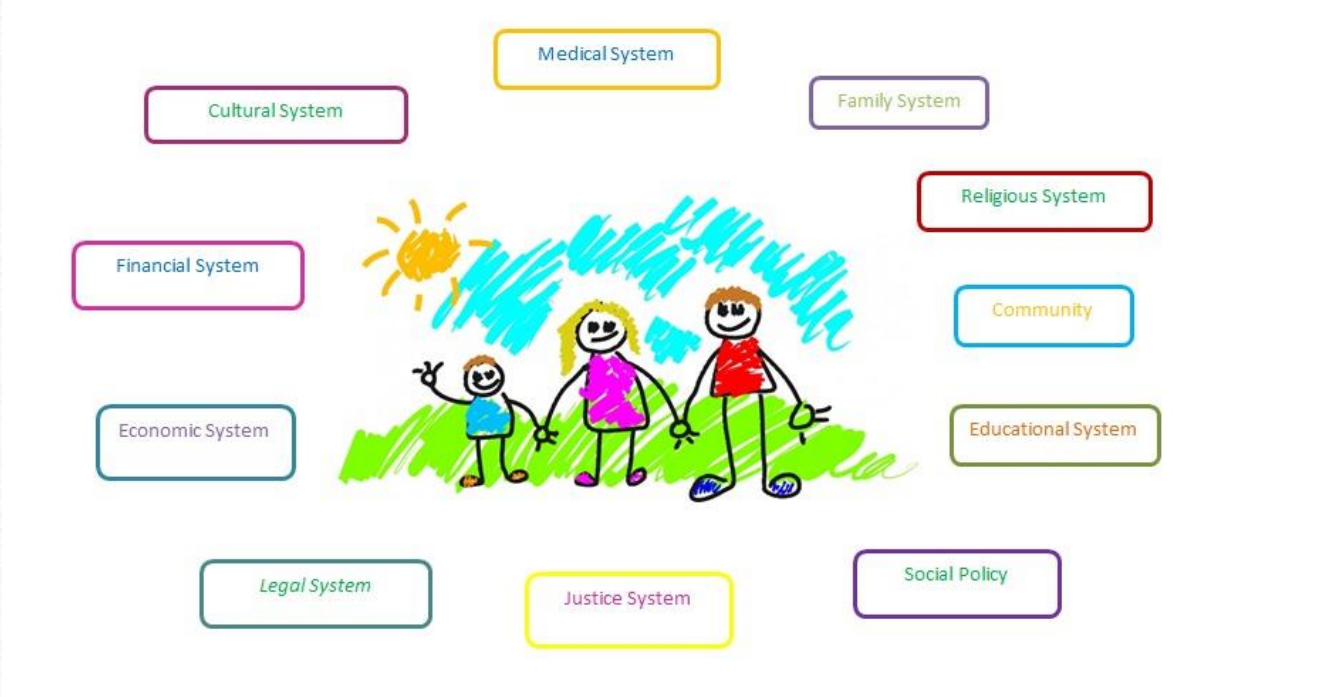
Support before death – what do we need to know?

- Theories of bereavement emerged from a psychoanalytic tradition and have been very medicalised with an 'intrapsychic' or intrapersonal approach.
- This gave rise to an individualised approach almost with an expectation of a defined pathway of 'necessary' stages in a progression to closure or recovery from or resolution of grief.
- Grief is *now* appreciated as a situated and profoundly social experience, as the bereaved …seek meaning in … personal and familial, and….broader community and even cultural spheres" (Neimeyer, 2014) with a recognition of the value of narrative in the construction of meaning (Walter, 1996)
- **Entirely consistent with a systemic approach in which social work practice is embedded**

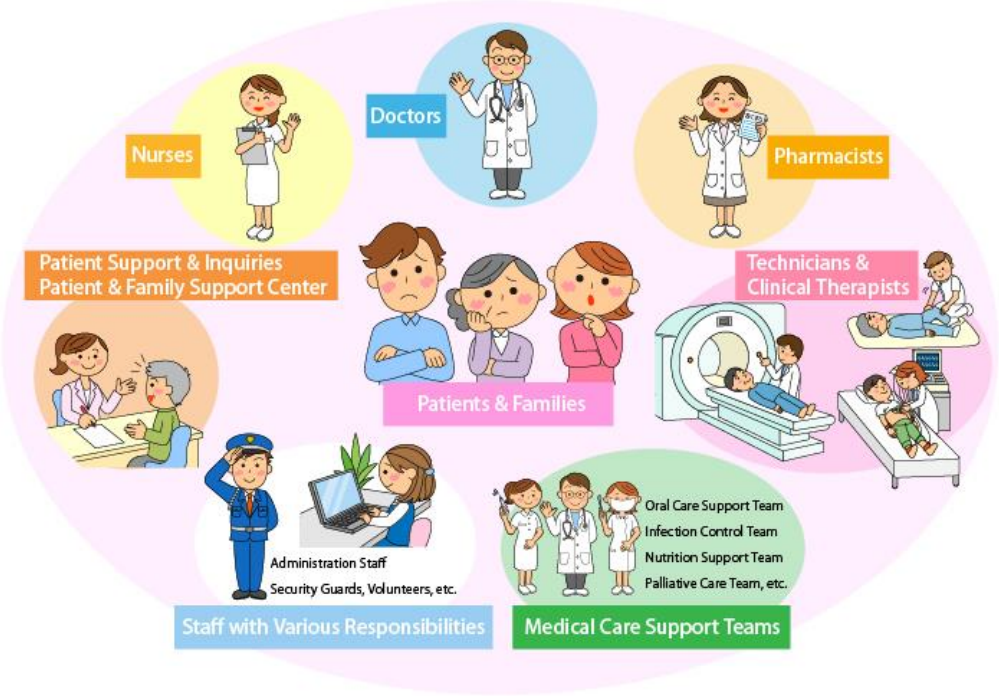
Social work, grief and Covid 19

- Social work as an 'Attachment Based' profession
- Social work is systemic in its focus on the individual in context, at the micro, meso and macro level
- In particular social work locates at the interface between the individual and society – mediating, advocating, integrating, supporting, communicating, regulating
- In healthcare – at the interface of the individual and the health care system(s)

Social work, grief and Covid 19



Social work, grief and Covid 19



Loss, Grief & Bereavement and pre-death care – what do we need to know?

In order to predict who might need help after the death:

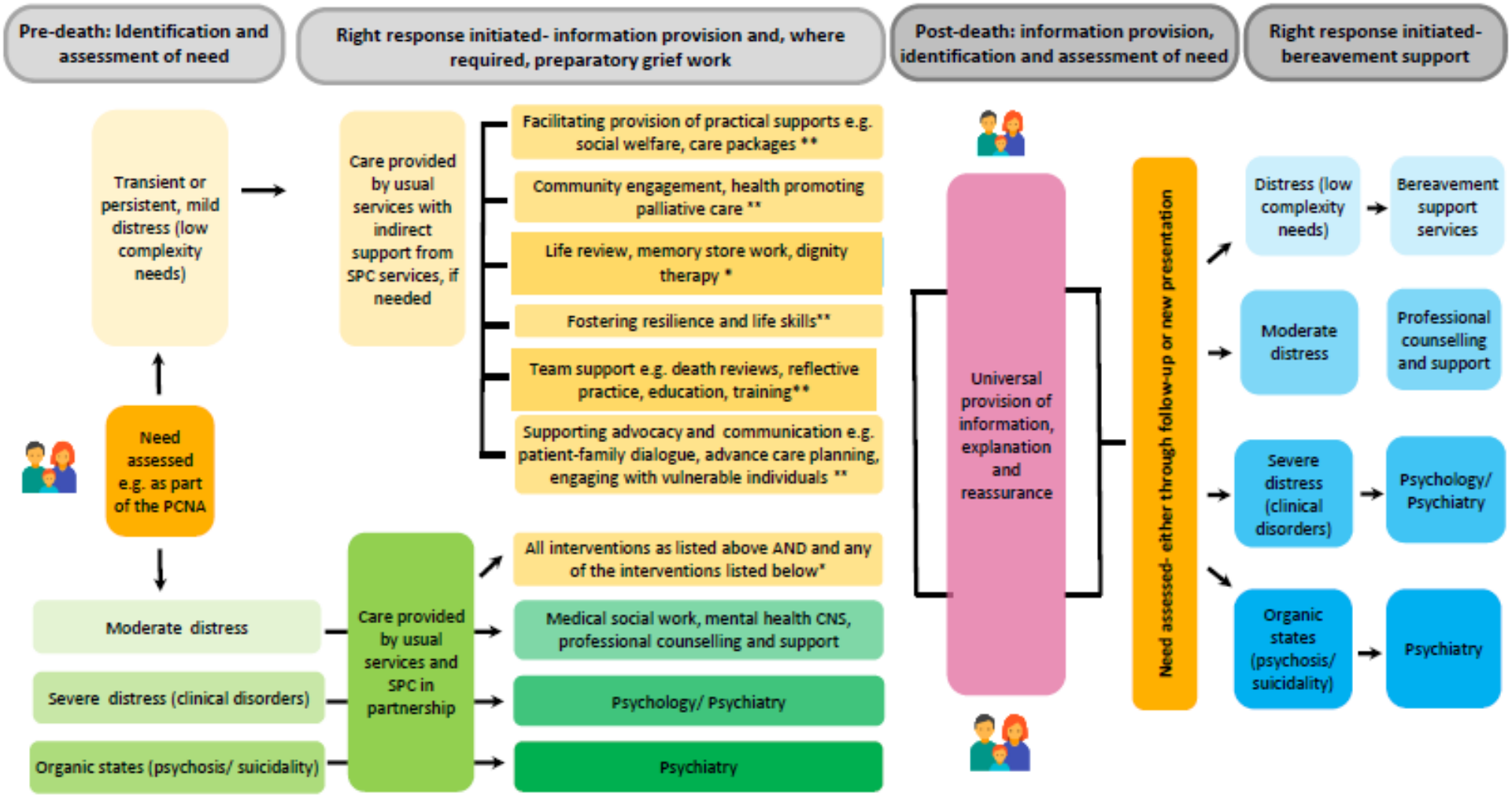
- empirical studies have focussed on identifying pre-death factors linked to poor outcome after death.
- In palliative care, these insights inform care of the family *before* the death in order to reduce the risk of complicated grief later.
- **End of life care during covid and end of life care when dying OF covid**

Loss, Grief & Bereavement and pre-death care – what do we need to know?

Seeing the patient within the context of his/her family means –

- We can offer strategic support to patient **and** family at a difficult time in their lives, using resources to best effect
- It gives the possibility of using **family** strengths and resources as part of patient care as well as identifying vulnerabilities, pre-existing or emerging due to covid
- We must be sensitive to their reports of experiences of other services and mindful of difficulties being experienced by other providers
- May be preventive for the family – we may be able to influence the end-of-life experience of family which may be of benefit in the longer term and may influence the family's capacity to cope with future crises

PATHWAYS - 4. Loss, Grief and Bereavement Pathway



PCNA: Palliative Care Needs Assessment; SPC: specialist palliative care;
** Preparatory grief work interventions

Risk factors for *complicated grief* (Lobb, 2010) and *post-loss depressive* symptoms (Nielsen, 2017)

- Loss a child (Lobb, 2010)
- Spousal loss at a young age (Nielsen, 2017)
- History of previous multiple losses and life struggles (Lobb, 2010; Nielsen, 2017)
- Lack of preparedness for the loss (Lobb 2010, Nielsen, 2017)
- High levels of care-giver burden pre-death (Nielsen, 2017)
- High levels of pre-death distress and depressive symptoms (Nielsen, 2017)
- High levels of family conflict (Kissane, 2016)
- Financial distress and poverty (Newsome, 2017; Nielsen, 2017; Roulston et al, 2016)
- Lower levels of educational attainment (Nielsen, 2017).

Risk factors and implications for pre-death care during a pandemic

- Who has been carrying heavy burden of care for a long time? *This may have been additionally impacted by a lack of community supports or by the choice to remain at home for as long as possible because of visiting restrictions....*
- Who seems to be particularly distressed or depressed in the lead up to death? *Was social isolation an additional factor with lack of contact from family, friends and neighbours? Are there mental health concerns? Has anyone else in the family contracted covid 19?*
- Who is carrying extra burdens? Or has experienced other significant losses? *Are there others in the family needing care? Is someone in the family home schooling? Are there other stresses present eg domestic violence? Excessive alcohol intake? Adult children returning to the family home?*

Risk factors and implications for pre-death care during a pandemic

- Does this family realise the seriousness of the illness? All family members? *Exploring families understanding and assessing gaps in information and understanding. Is there anyone being left out? Linking with medical and nursing colleagues. Are there concerns about the route of transmission if the patient has covid 19? Blame?*
- What about socio-economic disadvantage? *Has covid impacted on employment and income? Do social circumstances make self-isolation or cocooning very difficult? Or make care at home difficult?*
- Are family members able to manage being together in stressful circumstances? Conflict about nature or place of care? *Carer fatigue is significant and tensions may be elevated. May be longstanding conflicts which we will never solve but must help them to manage*

Risk factors and implications for pre-death care during a pandemic

- Are there concerns being expressed by family about care/treatment decisions or provision? Ambivalence or conflict among family members? Between family members and team? *Some of this will be irretrievable…*How can these be addressed and by whom? when?
- Are family members reporting traumatic experience with what they perceive as aggressive and/or inappropriate/unsatisfactory treatments? *What can we do to help? Are there heightened levels of anxiety because of the ongoing of the pandemic and particularly because of 'wave 3' impacting on coping generally?*

Pre-death care during a pandemic- service provision and ethical practice?

- Assessment in *collaboration* with the family in terms of their unique strengths, resources and vulnerabilities and exploration of their concerns and gaps in their understanding. **Values and diversity** √
- Communication with the family, with the team. **Partnership** √
- Identifying strengths and resources in family constellation, focussing in empowerment and respect **Ethics** √

Pre-death care during a pandemic- service provision and ethical practice

Social Work is a profession that:

- Values communication and connection to support wellbeing and development (Casey, 2020).
- With visiting restrictions this becomes a **key activity** for all team members
- Enabling patient-family communication via virtual means ….. clear communication from healthcare staff and facilitating relatives to say 'goodbye' are associated with better outcomes in bereavement (Selman et al, 2020). **Access** √

Pre-death care during a pandemic- service provision and ethical practice

- Must become well versed in using technology (McGarry & Casey, 2020).
- Raises issues of access to, and literacy in technology
- Now having personal and challenging conversations by Zoom, Microsoft Teams and now, Attend Anywhere.
- Raises issues of confidentiality and equity and best practice. How can we work around these issues? **Ethics** √

Connecting patients, families and teams

One size does not fit all……..

- Virtual connection between patient and family – using 'whats app', 'facetime' Instagram, skype, zoom. *Not natural in our practice, respect for individual preference and considering confidentiality particularly for people who need assistance to partake. Ask for who's benefit…*
- Playlists and photographs (electronic and physical) *happy mementos, painful reminders of loss and lack of privacy*
- Virtual connection between team and family *does everyone have access to technology? Time zones? preparedness*
- Multiple connectivity – zoom *family 'get-together', company, support and virtual presence (at end of life. View of colleagues re same? Managing expectations?*

Connecting patients, families and teams

- A word about advocacy – in times of restricted visiting, often visits are facilitated when the person is coming to end of life. Is that the best time for a precious visit?
- Otani et al (2017) found that being present at death did not impact of rates of complicated grief BUT the opportunity for meaningful conversation (when the person is still well enough) was associated with reduced symptoms of depression and complicated grief. (pre-covid study)

Pre-death care during Covid

- Be aware of **language** - this is not what you imagined it would be.. Or how we want it to be.. How we can create sharing time, memories or legacy through phone/skype/zoom.
  - Record messages on a smart phone to give to family
  - Can patient dictate a note that can be given to family?

  Perhaps there are ways that we can create presence even if you are physically distant. Can you tell me about them as a person?

  - Think of ways to reminisce, share feelings and create a soothing environment (prayer, music, a favorite movie, reading a book over the phone etc.) Do they have pictures or a favorite object at home that we could put in the room to provide comfort?

Pre-death care during Covid

- Reinforce that memorials & memories transcend time and when travel is allowed again there will be a way to honor their legacy in person. Psycho- education focused on the procedures and community resources that are evolving related to deaths from Covid 19
- Listen for the unique responses of patients – worry, fear, anger, relief, care preferences & gives honest information, align expectations.
- We have placed you on special isolation to keep you safe…..
- If death is expected, engage family to share and adapt their hopes for the death they had imagined and maximize what is possible to create. (Keleman, 2020)

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To access the documents:
Guidance for Bereavement Support provided by Specialist Palliative Care Social Workers in Ireland,(Oct 2019) and Addendum - COVID-19 (2020)
http://www.professionalpalliativehub.com/resource-centre/guidance-bereavement-support-provided-specialist-palliative-care-social-workers