

# CareSearch Engagement Activity

Action Plan: Patients, Carers, and Families.

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CareSearch is funded by the  
Australian Government Department of Health.

## CareSearch and palliAGED Engagement Project

- Building knowledge and awareness through sector engagement
- Three specific groups:
  - Allied Health
  - Aged Care
  - Patients, carers and families



## CareSearch Engagement Project

- Understanding the Patient, Carer, Family context
- Facilitated discussions in workshop





## We asked: how do patients, carers, and families learn of new information?

### Sources include:

- Family/friends, Doctors, health services
- “Dr Google”, Mass Media, Social Media,
- Advocacy and support groups
- Public Libraries and Adult Education courses



### Challenges:

- Few central organisations; variations in individual experiences; lack of information awareness prior to crisis point.



We asked: how do we get information to where it is needed?

- Mass media (e.g. TV/radio segments)
- Social media (e.g. Facebook, blogs)
- Information displayed in waiting rooms and public libraries
- Interaction with community and advocacy groups
- Use stories to make it *real*





## We asked about the role of trustworthy information

- Trustworthiness is not the principle factor
- Trustworthiness is based on *WHO* says it
- People seek information that fits their current mental frame
- Interpersonal communication still preferred
- But, “Dr Google” increasingly used



## We asked about the role of trustworthy information



Challenges in relation to trustworthy information:

- Distress affects capacity to judge trustworthiness
- Education, technology skills, and health literacy influence trustworthiness judgements
- Volume of information
- Access to research findings



## We asked: what are your palliative care needs?



- Better communication about death for all ages
- Misunderstanding exists on what palliative care is
- Palliative care expectations, options, roles
- How to advocate and coordinate care for self and loved ones
- List of questions to ask - What do I need to know and when?
- Planning Information: Legal, Financial, Advance Care Planning





## And what about CareSearch/palliAGED?

- Not well-known
- CareSearch is trustworthy - good quality information
- Helpful information there, but takes a while to find it
- Navigation challenges
- Needs more ways to interact
- Need clarity on CareSearch's role for Patients, Carers & Families



## Your 'blue sky' suggestions\* revealed 7 themes:

- Improve website navigation
- Develop new information/presentation formats
- Interactive feedback options
- Educational opportunities
- Better linkages
- Strong marketing campaign
- Structural changes



*\* We asked if there were no restrictions, what could CareSearch do to better support and interact with your sector*

## What we propose to do – Action Plan

Our priorities for the next 12 months:



1. Help people needing palliative care to be aware that CareSearch exists and can help, by promoting our resources:
  - Based on 6 key topics raised in workshop
  - Promotion via social media, public libraries, short articles for media and community newsletters

## Key Topics to be covered in campaigns (in proposed order of priority):



1. What is palliative care? What can it offer?
2. Caring and Advocating
3. Pathways through palliative care
4. Getting prepared – conversations & questions to ask
5. Talking about death and dying
6. e-Health Literacy tips

## Information Channels to reach people through:



### **Media outlets:**

- FaceBook Adverts
- ABC Radio and podcasts
- ‘The Conversation’ news
- ‘Starts at 60’ news and blogs
- ‘The Senior’
- Print Magazines

### **Local Channels:**

- Public Libraries
- GP waiting rooms
- Community Centres

### **Newsletters & FaceBook pages of:**

- National/State Carers Associations
- National/State Palliative Care Organisations
- Community groups (CWA, Rotary, Probus, RSL, Lions, community centre newsletters)
- National/State Seniors Associations (Seniors Card e-news, 50 something mag, HelloCare mag, Your Life Choices)
- National/State Advocacy Organisations (CHF, COTA, OPAN, Aged Care Alliance)
- Specific Health Associations (Dementia Australia, Pain Australia, Cancer Council, Cancer Voices, Kidney Health Australia, Raising Children Network, Lung Foundation)

## What we propose to do – Action Plan

Our priorities for the next 12 months:

2. Improve website navigation and interactivity
3. Promote linkages with peak organisations



The workshop was a rich source of ideas. Ideas that are out of scope of this current 12-month project have been noted and will be used as part of planning of future work.

## What we propose to do – Action Plan



For some of the action items, having community members contribute by sharing stories, writing articles or reviewing content will be important.

So if you are keen to be involved please let us know by sending an e-mail to

[CareSearch@flinders.edu.au](mailto:CareSearch@flinders.edu.au)  
[lauren.miller@flinders.edu.au](mailto:lauren.miller@flinders.edu.au)



## Engagement Project –next steps



- Implementation and Evaluation phase
- Second workshop next year
- Your continued input and involvement is important to us
- Ongoing feedback and comments always welcome





# Thank you!



To keep up-to-date, **register to receive** [@CareSearch](#) or [palliAGED news](#)

We value your input. Please contact us any time with your suggestions:

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