CareSearch@10:
Making palliative care evidence evident



CareSearch is funded by the Australian Government Department of Health.

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CARESEARCH®
palliative care knowledge network

Flinders UNIVERSITY

CareSearch: 10 years of providing palliative care evidence to all Australians

In 2014, the first ever global resolution on palliative care, called on the World Health Organization and its member states to improve access to palliative care as a core component of health systems, with an emphasis on primary health care and community/home-based care. This provides the framework within which care for people at the end of life needs to be framed.

It means that all health professionals need to be involved and that the care setting is not just hospitals and specialist palliative care services but all the places where people live and die.

This speaks to the heart of CareSearch's role and contribution, ensuring that all health professionals and care providers as well as patients, carers and families have easy access to trustworthy, evidence-based information.

Evidence enables us to make informed decisions by helping us understand the likely results and the potential benefits and harms of a treatment at a professional and a personal level. It can help us to understand how best to provide care and support patients and families. It provides a basis for assessing and supporting continuous improvement within services. Evidence also highlights the areas where increased investment or targeted investment could be most beneficial.

For 10 years CareSearch has been assembling and disseminating evidence, becoming the major online source for palliative care evidence in Australia. We do the valuable work of continuously identifying, evaluating, synthesising and disseminating trustworthy information and best available evidence on palliative care.

CareSearch provides tailored information for all Australians, including those in rural and remote areas, Aboriginal and Torres Strait Islanders, LGBTI, different cultural groups, prisoners, and people with intellectual disability and experiencing mental illness.

We seek to innovate, to work with others in the palliative care community and to use new technologies to communicate and engage with those who need palliative care evidence and information. Our award-winning Dying2Learn online course has helped more than 4,000 participants to learn and overcome the difficulty in talking about death, dying and palliative care. Over 100,000 Australians make use of our website resources each month and our resources are embedded in more than 10,000 other webpages and distributed to an average of 150 organisations annually.

Moreover, our palliAGED website and resources help the aged care sector deliver quality palliative care by providing online evidence-based guidance and practice resources. We also help expand the evidence base on palliative care through our own research and by enabling researchers to easily find studies and published information.

Over the next three years, we will continue to make palliative care evidence evident and accessible for all Australians. We are leading an engagement project to identify and address the information needs of patients, carers, families, allied health professionals and the aged care sector. Our palliAGED apps will be updated to reflect a new framework, resources and evidence. We will also release a new education module to help aged care staff apply evidence when providing palliative care.

Professor Jennifer Tieman

Director, CareSearch palliative care knowledge network and Matthew Flinders Fellow
College of Nursing and Health Sciences
Flinders University



What is palliative care?

A person and family-centred form of active and supportive care that seeks to maximise quality of life for people with a life-limiting illness.

BENEFITS

- Offers a support system to help you live as well as possible
- Can help you get optimal care based on your needs, preferences, values and available resources
- Provides relief from pain and other physical and emotional distress

Benefits of quality palliative care

For patients

- Offers a support system to help you address the physical, emotional, financial, social and spiritual challenges brought by the patient's illness
- Prepares you for what to expect and to participate in making decisions
- Can help cope with grief and bereavement

For carers and families

- Helps provide better care through improved symptom control, pain relief and comfort for both patients and their families
- Helps reduce stress from hospital admissions

For health professionals

- Enables a multidisciplinary team approach to address the needs and preferences of patients and their families
- Helps manage symptoms to minimise impact on activities of daily living
- Helps manage acute deterioration
- Helps with anticipatory prescribing and care planning at end of life
- Can help support families and provide culturally respectful care

For health and aged care providers

WITH WHOM

Palliative care can support people across all ages and all communities by working together with health, community service and aged care providers.



WHEN

DIAGNOSIS | TREATMENT | END OF LIFE | BEREAVEMENT

All health professionals can help provide palliative care when it is needed. Palliative care specialists help those with complex needs.

Why is evidence important?

Evidence is crucial in delivering the most appropriate and person-centred quality palliative care for all Australians.

Helps us understand the potential benefits and harms of a treatment or intervention

Empowers everyone to ask informed questions and make informed decisions

Provides insights to the most likely outcome of a treatment or intervention across a population



Understanding that palliative care is based on evidence makes consumers more confident about being referred to palliative care

Serves as the basis to drive continuous quality and service improvement

Highlights the need for investment, research and improved services

What is CareSearch?

The website is designed to help:

PATIENTS, CARERS AND FAMILIES

- Understand what palliative care is and isn't
- Understand, plan and manage issues when living with a life-limiting illness
- Feel confident to ask questions and make informed decisions
- Locate and access other palliative care resources and services

GPS, NURSES, SPECIALISTS & ALLIED HEALTH PROFESSIONALS TO ACCESS

- Critically appraised and summarised clinical evidence for best practice
- The latest systematic reviews on 135 palliative care related topics
- Tools and resources to help with clinical decisions
- Search filters to easily identify research findings within PubMed and grey literature
- Quality palliative care resources you can recommend to your patients and their carers
- Latest research findings and gaps for further studies
- Education and professional development resources

Information for specific community groups:

- Aboriginal and Torres Strait Islanders
- Rural and remote residents
- Children
- Lesbian, gay, bisexual, transgender and intersex patients
- Culturally and linguistically diverse patients
- People with disability
- Homeless
- Prisoners
- Dementia patients
- Young carers

HEALTH & AGED CARE PROVIDERS TO FIND

- Apps, tools and resources for health and aged care settings
- Critically appraised and summarised evidence for the aged care context
- Education and professional development resources to improve team and workforce capacity

CareSearch is the online source of palliative care evidence for all Australians.

2,700+	Systematic reviews on 135 topics	**140K+**	Page views per month	**2,000+**	Twitter followers
40	Systematic reviews added per month	**120K+**	Web visitors per month	**20+**	National and local palliative care programs supported
200+	Studies saved in the research register	**3,500+**	Newsletter subscribers		

CareSearch: The work that we do

ENSURING YOUR 24/7 ACCESS TO THE BEST AVAILABLE EVIDENCE

Palliative care covers many diseases and uses different treatments to address physical, emotional, social, spiritual and other needs.

Finding the best available evidence is difficult and time consuming because:

- The number of studies has grown exponentially in the past decade
- The literature covers numerous topics, journals and databases
- There is lack of consistent terminology and descriptions
- Relevant studies are not always listed as palliative care
- Some questions are difficult to answer

What we do:

- Identify and screen over 500 systematic reviews per month
- Add over 40 systematic review studies per month
- Update over 40 webpages per month
- Add over 40 reports, guidelines and conference abstracts to the grey literature per month
- Promote our website and resources

Why we do this:

- To highlight the latest findings
- To synthesise new implications of certain treatments and interventions to patients and services
- To provide access to current areas for further research

BUILDING CAPACITY BY CONNECTING THE WORKFORCE TO EDUCATION

CareSearch helps to build capacity and understanding through palliative care education.

WE:

- Identify, develop and share information on education and training options
- Help the workforce navigate learning choices in the Education section
- Deliver online professional learning courses, including the award-winning Dying2Learn
- Host a range of national and local professional education programs

SUPPORTING THE PALLIATIVE CARE COMMUNITY

CareSearch works with many organisations and programs in Australia.

WE:

- Host and provide technical support to more than 20 palliative care initiatives through our website
- Contribute our expertise to national and local projects
- Link palliative care initiatives and professionals

STRENGTHENING PALLIATIVE CARE RESEARCH IN AUSTRALIA

Research is essential for improving the quality of palliative care.

WE:

- Enable researchers to share information, collaborate and prevent duplication through our research register
- Connect people to the latest, relevant research with search filters for PubMed
- Support new researchers to design and action their study
- Conduct research to build palliative care knowledge

Our work over the years

2008

CareSearch Launch

CareSearch, the online source for the current evidence on palliative care, was launched to provide all Australians 24/7 access to trustworthy information.



2009

Patient-Families and GP Sections

CareSearch created its Patient-Families section to provide practical and evidence-based advice and resources for those living with or caring for someone with life-limiting illness. A specialised GP section was also developed to enable doctors to provide quality palliative care and support to patients and their families.

2010

Nurses section; Heart Failure Search Filter; and Resources for Italian, Greek and Cantonese communities

CareSearch created the Nurses section to support them in providing the best possible palliative care to patients and their carers. The Heart Failure Search Filter was also developed to assist health professionals find the latest evidence efficiently. To address the needs of cultural communities, CareSearch translated its resources into various languages. Italian, Greek and Cantonese videos were the first to be released.

2011

My Learning Modules, Lung Cancer Search Filter, National Standards Assessment Program support

CareSearch released the first My Learning Modules to support the professional development of doctors, nurses and allied health workers on palliative care. The Lung Cancer Search Filter was also added to enable health professionals find the latest evidence quickly and efficiently. CareSearch also worked with Palliative Care Australia to support the National Standards Assessment Program which aimed to improve the quality of services across Australia.

2012

Residential Aged Care Hub/Section

CareSearch created the Residential Aged Care section to support and enable staff to provide quality care for older Australians at the end of life.

2013

Allied Health section, Telehealth Trial with Flinders University, and Needs Assessment Tool for Carers

Recognising that allied health professionals are essential to palliative care, CareSearch added the Allied Health section to ensure that professionals working in this important area can provide evidence-based and person-centred support to their clients. CareSearch also lent its expertise and supported the Telehealth Trial with Flinders University.



2014

Aboriginal and Torres Strait Islander pages and My information kit

CareSearch developed the Aboriginal and Torres Strait Islander pages to help health professionals deliver culturally responsive care. The My Information Kit was released to help doctors provide evidence-based information for their patients needing palliative care.

Our work over the years Continued...

2015

palliAGEDgp and Palliative Perspectives

In partnership with Decision Assist, CareSearch launched the palliAGEDgp app. The free app provides doctors evidence-based information and prescribing guidance in both smartphone and web-based versions. The CareSearch blog, Palliative Perspectives, also started.



2016

Dying2Learn and palliAGEDnurse

CareSearch created the Dying2Learn Massive Open Online Course to enable all Australians to learn, talk and plan for dying, death and palliative care. In partnership with Decision Assist, CareSearch launched the palliAGEDnurse, a free app that provides all Australian nurses with 24/7 evidence-based information for supporting patients approaching the end of their life.

2017

palliAGED website, Dying2Learn Award and CareSearch refresh

CareSearch created the palliAGED website to support health professionals working in the aged care sector. The website ensures easy access to an evidence base for care, practice and service delivery. CareSearch's Dying2Learn online course was given the National Innovation in Palliative Care Award. In response to the changing needs of its users, CareSearch refreshed its website and resources.

2018

ELDAC website and toolkits

CareSearch is part of the ELDAC Consortium and released the ELDAC website and toolkits to help improve aged care outcomes.

TEL website

CareSearch partnered with Sydney University to build the TEL website, an end of life resource to help people with intellectual disability.

CareSearch Engagement Project

CareSearch leads an Engagement Project to enable more Australian health professionals and consumers access and use evidence-based palliative care information.

caring@home Project

CareSearch partners with Brisbane South Palliative Care Collaborative to create a new online resource supporting carers to provide medications in the home.

2019

Australian Carer Toolkit for Advanced Disease

Working with St Vincent's Health, CareSearch will build a new toolkit of evidence and resources for family carers.

ELDAC digital dashboard

CareSearch will help to create a dashboard of end of life indicators for aged care.

palliAGED apps updated

The palliAGED apps will be updated with a new framework, resources and evidence.

palliAGED My Learning module

CareSearch will release a new My Learning module showing aged care staff how to use palliative care evidence.

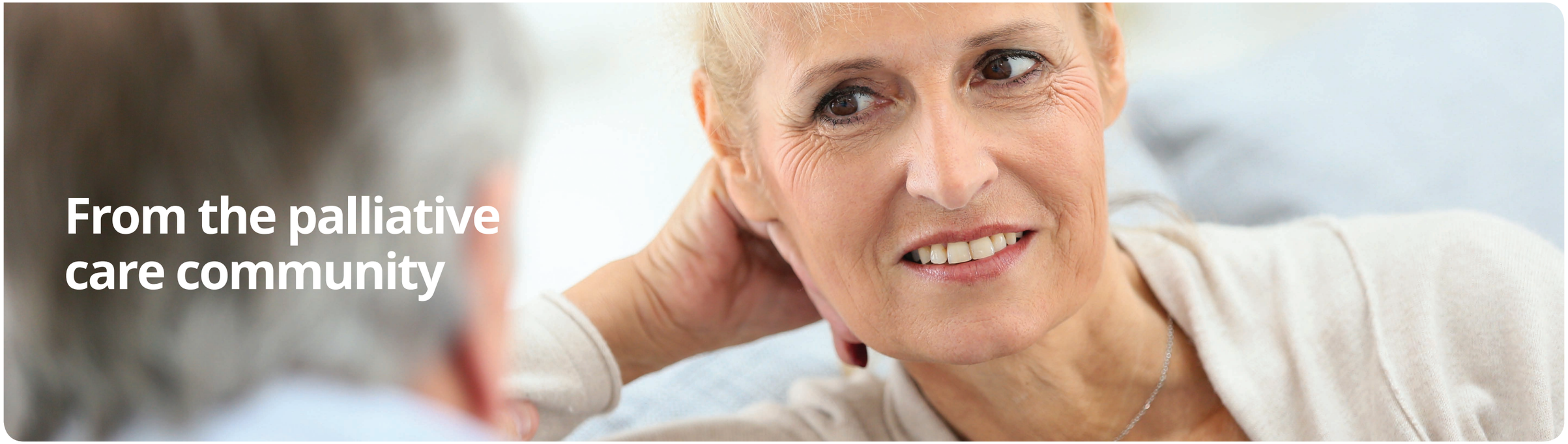


2020

CareSearch Engagement Framework

Findings from the CareSearch Engagement project will be released.





From the palliative care community

CareSearch: The pathway to informed end-of-life care

Professor Imogen Mitchell
Dean, The Australian National University Medical School

As a practising intensive care specialist for over 21 years, I have had the privilege to be with many patients and families during one of the most difficult times of their life. Difficult because intensive care can be a terrifying, confusing and bewildering experience with a strong sense of losing control over decisions including life and death. For patients and families to make sense out of an almost impossible situation, **it is critical for the intensive care physician to articulate the story clearly.**

This allows the patient and family to have a solid understanding of their situation and simultaneously create opportunities for further clarifying questions. This shared understanding can be used as a platform for further decisions particularly around end-of-life care, which are informed and create a sense of ownership by the patient, and if possible, also the family.

One of the luxuries I have, as an intensive care physician, is having a greater amount of time to talk to patients and families. For many patients and families it is often difficult to access healthcare professionals with time and knowledge about end-of-life care or the palliative approach to care.

From my days as a junior doctor to those as a director of intensive care, I have long appreciated the value of evidence to inform decisions not only about individual patient care but the use of evidence in business discussions to improve the delivery of health care.

A way of accessing trustworthy information about the palliative approach to end-of-life care can be found in CareSearch. It enables patients and families to have a better understanding of what is happening and help them with decisions, which will need to be made when they meet with their health care professionals.

CareSearch provides invaluable, up-to-date evidence on all aspects of end-of-life care, which helps clinicians like myself, to provide the best care based on the best available evidence. For a busy clinician and an end-of-life care researcher, CareSearch affords incredibly easy access to relevant literature, which can often be hard to find. CareSearch is a wonderful aid to both senior and junior researchers alike.

As we all continue to strive for our desired goal for all Australians to die symptom free in a place of our choice and with those we choose to be with, CareSearch adds a depth of knowledge to end-of-life care, which is nation-leading. As health care professionals and as members of the community, CareSearch can only add to achieving our desired goal.

Evidence crucial for making informed clinical decisions

Professor Jane Phillips
Professor, Palliative Nursing and Director, Improving Palliative, Aged and Chronic Care through Clinical Research and Translation
Faculty of Health, University of Technology Sydney

As a registered nurse with personal and professional palliative care experience, I am acutely aware that our patients and their families expect to be provided with the best evidence-based health care throughout their entire illness trajectory. However, the large volume of new research that is generated on a daily basis make keeping abreast of the evidence challenging for most of us.

In a speciality like palliative care where the evidence is rapidly evolving and old practices are being called into question, it is essential that all health professionals caring for patients with palliative care needs have the capabilities to both promote and implement new evidence, as well as support the de-implementation of outdated practices. Letting go of obsolete practices is central to reducing health care waste and costs, which is now a global priority.

Interestingly, my academic journey was triggered by a recognition that if I was to be the type of palliative care nurse that my patients needed, then I had to be a better consumer of the evidence. That is a palliative care nurse who having assessed my patients' care needs and identified their priorities, could frame a focused clinical question. I wanted to be able to independently acquire the evidence needed to answer the specific clinical questions, independently search and critically appraise the identified evidence.

Fortunately, for me and for many nurses like myself, CareSearch has made searching for the palliative care evidence so much easier. With its extensive collection of palliative care search filters, CareSearch enables busy health professionals to rapidly obtain the relevant evidence so we can apply our critical appraisal skills.

Each and every one of us owes it to our patients to ensure that our clinical reasoning is informed:

1) by the best available evidence;

2) draws upon our clinical experience, skills and education;

3) considers each patient's individual situation, taking into account their personal values and needs; and

4) considers the context in which care is being provided and any cost constraints.

It is crucial to remember that evidence-based practice is not just only about the evidence. It will only occur when all of these four elements are integrated to arrive at the best treatment/care decision for each patient.

Happy Birthday CareSearch. Thank you for making the palliative care evidence so easy to access. I look forward to what you will deliver in the next 10 years.



From the palliative care community Continued...

Providing person- and family-centred palliative care for a culturally diverse Australia

Ms Mary Patetsos
Chairperson, Federation of Ethnic Communities' Councils of Australia

Australia is a dynamic multicultural country. Ours is a nation that is home to one of the world's oldest culture and millions of people belonging to 270 ancestries. There is no doubt that our country's progressive economic, cultural and social landscapes have been enhanced by contributions of culturally and linguistically diverse (CALD) Australians.

As with the general population, the number of CALD Australians has increased in the last few years. The 2016 Census[1] showed that over 6 million Australians were born overseas, comprising 26% of our entire population. The top countries of origin include England, New Zealand, China, India, Philippines, Vietnam, Italy, South Africa, Malaysia and Scotland. This increase is also true in terms of the number of older Australians, with 36% of those aged 65 and over having been born overseas[2].

Recently, there has been a re-emphasis on a person- and family-centred approach towards palliative care. Defined as an approach that is *"strongly responsive to the needs, preferences and values of people, their carers and families"*[3], a person- and family-centred palliative care clearly needs to be culturally sensitive and safe. This approach also emphasises the need for evidence to improve the quality and delivery of palliative care.

The Federation of Ethnic Communities' Council of Australia (FECCA) has long been working to help provide older CALD Australians culturally-appropriate care and services. We have been conducting advocacy and research initiatives to identify areas for service improvement for older CALD Australians.

We know from our own research[4] that older CALD Australians face more challenges. These include socio-economic disadvantages, English language barriers, cultural translation difficulties, lack of exposure to Australian services and systems, and lower rates of access to services. CALD carers and family members also use lower rates of support services.

We need quality evidence to be able to address the needs and challenges faced by our older CALD Australians and provide them person and family-centred palliative care. We need to continue to research, improve the comparability of results, increase the research participation of older CALD Australians, mine existing data sources and maintain the currency of the research database to ensure service and practice decisions can be based on the best available evidence.

Resources like CareSearch are very important in this regard. CareSearch does the valuable work of identifying, evaluating, synthesising and disseminating trustworthy information and the best available evidence on palliative care. It has a strict review, monitoring and feedback processes that ensure the quality of evidence and information it presents.

FECCA has been involved with CareSearch since its development. We are proud of the work that Helena Kyriazopoulos has done to represent FECCA and the voices of CALD Australians on palliative care. As an organisation, we are delighted to work together to help improve the palliative care journey of all CALD Australians. We congratulate CareSearch for reaching its 10th anniversary and wish it all the best in the future.

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2. Australian Institute of Health and Welfare. Older Australia at a glance [Internet]. Canberra, ACT. AIHW; 2017 [cited 12 July 2018]. Available from: www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/diverse-groups-of-older-australians
3. Palliative Care Australia. National Palliative Care Standards [Internet]. Canberra, ACT. PCA; 2018 [cited 12 July 2018]. Available from: www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/diverse-groups-of-older-australians
4. Federation of Ethnic Communities' Council of Australia. Review of Australian Research on Older People from Culturally and Linguistically Diverse Backgrounds. 2015 March [cited 12 July 2018]. Available from: fecca.org.au/wp-content/uploads/2016/02/AgedCareReport_FECCA.pdf

The power of knowledge

Ms Kim Devery
Project Lead, End-of-Life Essentials and Senior Lecturer, Flinders University

Teacher, facilitator and guide, that's my job at Flinders University. I guide doctors, nurses and allied health professionals in postgraduate studies, to assist them in understanding their own strengths and challenges and strengthen their capacity in delivering health care services to patients who are at the end of life. I also lead a major national education project, **End-of-Life Essentials**, which is free and evidence-based, and aims to increase professionals' skill and confidence in end-of-life care in acute hospitals.

The thousands and thousands of doctors, nurses and allied health professionals who seek Flinders University's education on end-of-life and palliative care work in various health care systems. Some of these health systems struggle to provide quality care at the end of life. Our students, aware and proactive professionals, seek to change their own capacity and the systems in which they work. They strive to be the change that is needed across Australia. Why is change needed?

Slow dying and death, in very old age caused by chronic illness is a relatively new phenomena. The rise of medical science, vaccination and public health measures like clean water have not only altered the way we live but also changed the way we die[1]. Today's leading causes of death are dementia, cardiac disease and cancer. In the 21st century Australia, people live with these chronic illnesses for many years before they eventually die.

These illnesses are not curable, but they can be managed by our health care systems for some time. This means of course that many older people may be aware at some level that they are at the end of life and this phase may continue for several years.

Today, older people have much time on their hands living with decreased physical function, ill health, dependency on others for day-to-day needs and an awareness of their own mortality[2].

However you don't need to go back one hundred years to see the change in our patterns of dying. Research by McNeil and colleagues[3], published this year, illustrates the dramatic changes in our mortality since the 1970s. These researchers compared the mortality rate of 100,000 men and women between 20 and 70 years of age spanning the decades 1960 -2010. What did they discover?

A dramatic shift in the age of when we die - 70 is the new middle age now. In 1970, 50% of men died before the age of 70 years, in 2010 only 18% of men had died before 70. Similarly, 28% of women had died before 70 and this has now fallen to 11%. This means that Australians are living with chronic ill health and significant disability for many years before they die. **Dying takes time, the rise of ageing and chronic ill health means that the majority of people in Australia, have a heightened sense (thinking, feeling and preparing) of their own end of life for many, many years.**

In being the change, **doctors, nurses and allied health professionals require trustworthy and up-to-date evidence to inform their practice and meet the growing needs of patients at the end of life.** These professionals are preparing to respond to questions and issues that go way beyond physical symptoms. Questions spanning existential, emotional and the social concerns and issues can be common when delivering care at the end of life[4].

Having conversations and responding to patient questions like "What will happen to me?" or "How long do I have left?" or "How do I tell my son?" require confidence. **Professionals look to CareSearch for the evidence to build their own confidence, knowledge and ultimately be the change that is needed by our population who is aged and dying.**

1. Jones, DS, Podolsky, SH, Greene, JA. The burden of disease and the changing task of medicine. The New England Journal of Medicine, 2012 [cited 20 July 2018]; 366: 2333-2338. doi: 10.1056/NEJMp1113569
2. Gale, D. Changing the choice architecture of ageing. The New Bioethics: A Multidisciplinary Journal of Biotechnology and the Body, 2014 [cited 20 July 2018]; 20(2), 124-140.
3. Curtis AJ, Ofori-Asenso R, Gambhir M, McNeil, J. Mortality among middle-aged Australians, 1960–2010: implications for prevention policy Med J Aust 2018 [cited 20 July 2018]; 208 (10): 444-445.
4. Smith R. A good death. BMJ: British Medical Journal 2000 [cited 20 July 2018] vol. 320, no. 7228, pp. 1-2.



From the palliative care community Continued...

CareSearch and primary and community care

Professor Geoffrey Mitchell
Professor of General Practice and Palliative Care
University of Queensland

The end of life is a time of high stress for patients and carers. It is a situation that everyone faces only once for themselves, and often only once for their carers as well. At a time when a person is suffering the symptoms of extremely serious disease, most of the day-to-day care is being offered by close relatives or friends with little or no knowledge or experience of such conditions.

They are frequently fearful of making a bad situation worse by inadvertently doing the wrong thing. Often there are multiple professionals involved in the care, and it is not uncommon for slightly different advice to be given by them to manage different situations. This causes confusion and more anxiety. The line of least risk for them is to transfer to hospital – a major reason for low rates of home care till death.

Furthermore, people are not really sure of what actually happens when a person dies. Will it be distressing? How do we best assist in minimising this distress? Finally, this is happening to someone that is usually greatly loved, and the spectre of loss looms darkly. It colours daily relationships, and can put significant pressure on both patients and carers if they do not understand what is happening.

For example, a full time GP can expect to see about 5-6 deaths per annum in the course of caring for over a thousand patients on average. It can be very hard to accumulate the knowledge needed to care for dying people well. With the population ageing, and people becoming more frail as they accumulate more health problems, more and more people will reach the end of life and the rate of deaths is set to more than double in the next 20-30 years.

Dying from frailty, multimorbidity, dementia or single organ failure will be how most of us will go. The process is not at all like the relatively rapid and dramatic deterioration seen in cancer patients, for which specialist palliative care services are so well equipped. Dying like this is firmly in the hands of GPs. Are they equipped to manage these mounting challenges?

End-of-life care is everyone's business. With basic knowledge, it is possible for all health professionals to provide it. Where do they turn to when that knowledge is needed?

For the last ten years, Caresearch has provided high quality, evidence-based knowledge, which is tailored to the needs of patients, carers and different non-specialist health professional groups. The content is carefully researched and reviewed before release. It is an invaluable resource.

It is the one-stop shop for resources and initiatives from Australian Government programs. This enables rapid and effective rollout of the latest programs and policy initiatives coming from government and academia.

End-of-life care is also an area with a rapidly expanding research base. CareSearch has acted as a repository for established knowledge, a clearing house for hard-to-source knowledge such as conference proceedings and theses, and a source of a suite of tools to assist in the planning and execution of research to expand that knowledge. It has developed search filters to ensure that relevant literature can be sourced quickly and efficiently from the vast databases at health practitioners' disposal. It provides research databases that can be used to collate research input from around the country and the world in real time.

Australia is ranked second in the world for the quality of care offered to people at the end of life just behind the UK. A major reason for this achievement is the comprehensive knowledge network that was established and is known as CareSearch. It serves the professional community well, as well as providing readily understood information to those in the middle of the challenges of suffering a life-limiting illness, or providing care for someone in that situation.

Congratulations to CareSearch on 10 years of peerless work in the field. Long may it continue!

CareSearch: Helping us see the wood for the trees again for our patients

Dr Chris Moy
Chair, Central Adelaide Clinical Council, Adelaide Primary Health Network and
Chair, Federal AMA Ethics and Medico-legal Committee

For all our good intentions in trying to provide compassionate end-of-life care for patients, most of us will acknowledge the daily grind of barriers in doing this. These hurdles are borne of a health and community care system broken up into a confusing mess of organisational and financially independent silos, often with imperatives which leave gaps or which are at cross-purposes with each other. And then there are the daily distressing needs of dying individuals and their families which we sometimes don't see, or, if we can see them, cannot quantify and therefore find it difficult to convince authorities to bring resources to bear to provide some relief.

Out of this comes a multitude of solutions to fix individual problems, plug individual system gaps, and efforts to research and quantify individual problems in the "system". Our good intentions drive us to develop solutions to fix the problems in front of us, but these efforts in themselves, although noble, can either become lost in an unmapped world, or become part of the problem in adding to confusion.

Much like a doctor who looks at his or her computer screen more than talking with their patient, for all our great efforts, it is easy to lose sight of the wood for the trees in our care of the dying patient in front of us, as we expend our efforts in trying to search and find solutions to each problem or crisis, rather than focusing on the emotional needs of the individual and their family. And if frustration settles in, things can deteriorate further.

This is why CareSearch is so important. It brings some sense to the world in mapping the wonderful work that has been done in doing the research, developing the resources, and in the setting up of services to improve the care of dying patients - which are otherwise wasted if they cannot be found. In being a one-stop shop to search and find what is needed, the proportion of energy expended in the search is less.

And maybe we can then take our eyes off the screen and back onto the human being in front of us. And see the wood for the trees again in caring for them.





From the palliative care community Continued...

CareSearch: supporting paediatric palliative care

Dr Anthony Herbert
Director, Paediatric Palliative Care Service, Division of Medicine
Children's Health Queensland Hospital and Health Service

My area of professional practice has related to Paediatric Palliative Care. I first became aware of CareSearch in 2009 when I attended the Australian Palliative Care Conference in Perth as a new medical consultant. **CareSearch developed particular resources including a subsection on paediatrics and searches of the paediatric literature. I was impressed by the ease of access to evidence based practice relating to palliative care via the website and information sheets.** I was also impressed by the focus on other vulnerable populations (e.g. Aboriginal and Torres Strait Islander patients) and particular professional groups (e.g. allied health).

Subsequent support that CareSearch has provided to paediatric clinicians has included housing of the Clinical Indicators that the paediatric palliative care services in Australia collect on the CareSearch Research Data Management System (RDMS). Various research studies have also utilised the RDMS including a study on end-of-life care in Paediatric Intensive Care Units and the role of ambulance services in caring for children with palliative care needs.

CareSearch have also partnered with the National Standards Assessment Program to run workshops on quality improvement for paediatric practitioners. A personal highlight for myself has been the increased collaboration between CareSearch and paediatric services after the commencement of the **Quality of Care Collaborative of Australia (QuoCCA)** in paediatric palliative care education in 2015. Like CareSearch, this project is funded by the Australian Government Department of Health through the National Palliative Care Projects.

CareSearch has helped QuoCCA develop a website (quocca.com.au) with the aim of being a resource for the education of health professionals working in paediatric palliative care. CareSearch has provided an attractive and excellent platform at minimal cost. I have had the pleasure of visiting the CareSearch office in South Australia (while attending the 2017 Australian Palliative Care Conference in Adelaide) and we have benefited from having CareSearch staff members attend the Lady Cilento Children's Hospital in Brisbane to provide training on how to maintain the website.

CareSearch has also engaged well with social media including Twitter, with linkages to research and blogs. This is also a personal interest of mine, and a way that I find out about new developments in paediatric palliative care on a daily basis.

On reflection, the utilisation of librarians and repositories of knowledge in palliative care (including the grey literature) is an innovative way of progressing the knowledge and practice of palliative care alongside dedicated clinicians, researchers and educators. PedPalASCNET (pedpalascnetlibrary.omeka.net) is a similar innovation that has been developed for paediatric palliative care practitioners and researchers based in Canada. We are appreciative in Australia of being able to integrate our paediatric knowledge and resources with CareSearch and access knowledge and expertise at the same time.

CareSearch: Easy and rapid access to reliable information

Professor Liz Reymond
Deputy Director, Metro South Palliative Care Service, Metro South Health Queensland

Who would have thought you would grow into such a big beautiful creature? I have watched you grow from a tiny baby with just a couple of pages and no teeth to speak of into a gorgeous site with apparently unlimited pages, well-proportioned functionality and what an attractive menu bar! You even have your own learning management system. You have mixed with the right crowd and your linkages with some 10,000 other valuable webpages are impressive. As you have grown digitally you have become indispensable to the palliative care sector and you support us all with your evidence-based teeth! I hope I am not embarrassing you, but all of us in the palliative care family are so proud of your growth and ongoing achievements.

Palliative care professionals and consumers need easy, rapid access to reliable information to make informed, often difficult, decisions about care. CareSearch acts as a repository for that information – either directly or through digital linkages.

CareSearch augments clinical efficiency and effectiveness by rigorously undertaking the time intensive, valuable work of identifying, evaluating, synthesising and disseminating quality information and best available evidence on palliative care. Clinicians respect CareSearch and know they can trust the information gained through the website.

Palliative care affects most people at some stage of their life. CareSearch is a valuable resource for these consumers by providing easy-to-understand palliative care information across a broad domain of issues.

Some of these important issues include: how to find a palliative care service, how to care for a palliative patient, and understanding and coping with grief, loss and bereavement. CareSearch tailors this information to suit as many Australians as possible including those living in rural and remote areas, people from Aboriginal and Torres Strait cultures, the LGBTI community, prisoners and those with intellectual disability and those experiencing mental illness. For many years, CareSearch has supported the aged care community to achieve best outcomes in palliative care.

CareSearch is active in expanding the clinical palliative care evidence base by supporting national, state and territory and local research projects. Importantly, it also conducts its own research across a variety of palliative care domains. Further, it provides palliative care education and tailors that education to the needs of various clinical subpopulations such as pharmacists, nurses, allied health professionals, general practitioners, hospital doctors and aged care professionals.

Over the years, CareSearch has become progressively more embedded into the palliative care sector. It is now well respected as an integral part of the sector and indeed regularly provides research and policy advice to various organisations and groups in the field of palliative care. Governments, peak bodies and jurisdictional policy and strategy units also request data and opinion from CareSearch staff.

CareSearch you truly are a great resource! It is hard to imagine the productive and innovative advances you will make in the digital palliative care space in the next 10 years.

CareSearch and the palliative care community: our linkages

CareSearch supports and collaborates with national and local initiatives to help improve the delivery of palliative care in Australia.

1. palliAGED
2. palliAGEDgp
3. palliAGEDnurse
4. Palliative Care Australia
5. Advance Care Planning Australia
6. End-of-Life Essentials
7. End of Life Directions for Aged Care
8. Advance
9. Palliative Care Outcomes Collaboration
10. Dying to Know Day
11. Planning Dementia Care through Case Conferencing
12. Life, Hope and Reality
13. Listen, Acknowledge, Respond
14. Palliative Care Clinical Studies Collaborative
15. NSW Paediatric Palliative Care Programme
16. Palliative Approach Toolkit
17. Quality Of Care Collaborative Australia
18. Palliative Care Education and Training Collaborative
19. Program of Experience in the Palliative Approach
20. Talking End of Life... with People with Intellectual Disability
21. Australian Carer toolkit for Advanced Disease
22. Centre of Research Excellence in End of Life Care
23. National Standards Assessment Program
24. Carer Toolkit
25. End-of-life care in residential aged care facilities
26. Flinders Filters
27. Telehealth in the Home Project
28. Paediatric Clinical Indicators Group
29. Decision Assist
30. KEG Link Nurse Study



palliAGED: palliative care evidence for aged care



palliAGED is an online suite of resources that was developed by CareSearch in 2017 to enable the delivery of quality palliative care for older Australians in aged care.

palliAGED provides the best available evidence, tools, guidance and practice resources about end of life and palliative care for older Australians.

palliAGED is a new way of presenting evidence-based guidance for aged care. It updates and replaces the Guidelines for a Palliative Approach in Residential Aged Care (APRAC) and the Guidelines for a Palliative Approach for Aged Care in the Community Setting (COMPAC) guidance documents.

palliAGED has:

- An Evidence Centre containing summaries on 35+ topics and information on symptoms, medicines, clinical issues and care practices
- A Practice Centre featuring evidence-based tools and resources
- Resources for older Australians and their carers and families
- palliAGEDgp and palliAGEDnurse apps that provides easy and convenient access to information in caring for people approaching the end of their life. Based on the Palliative Approach Framework Pathways of Care, the apps include practical information on:
  - Advance care planning
  - Terminal care management plan
  - Case conferences

palliAGED
PALLIATIVE CARE AGED CARE EVIDENCE

Visit caresearch.com.au to find the best available palliative care evidence.



CareSearch is funded by the Australian Government Department of Health.

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CARESEARCH® palliative care knowledge network

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