painaustralia

ROYAL COMMISSION INTO AGED CARE SAFETY AND QUALITY

FEBUARY 2019

Introduction

Painaustralia welcomes the opportunity to provide a submission to the Royal Commission into Aged Care Safety and Quality.

Painaustralia is the national peak body working to improve the quality of life of people living with pain, their families and carers, and to minimise the social and economic burden of pain. Members include pain and other specialists, health practitioners, health groups, consumers and researchers. Painaustralia works with our network to inform practical and strategic solutions to address this complex and widespread issue. The issue of safety and quality of care across aged care is an important one for us and our members. The consequences of untreated pain not only impact the individual person, but there is greater distress to their families and a greater care responsibility for staff.

With an ageing population (the Australian Bureau of Statistics projects that by 2064 there will be 9.6 million people aged 65 and over, and 1.9 million aged 85 and over, constituting 23% and 5% of Australia's projected population respectively[1]) the issue of effective pain management in aged care is an issue in the interest of every Australian.

Chronic pain is a common condition among consumers of aged care services and effective pain management should be a core responsibility of all providers. Unfortunately, evidence suggests many people with pain are poorly treated or under-treated.

Painaustralia's response covers the following terms of reference as listed by the Royal Commission:

a. the quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response;
b. how best to deliver aged care services to:
    i. the increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services;
c. the future challenges and opportunities for delivering accessible, affordable and high-quality aged care services in Australia, including:
i. in the context of changing demographics and preferences, in particular people's desire to remain living at home as they age; and
    ii. in remote, rural and regional Australia;
d. what the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe;
e. how to ensure that aged care services are person centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care related matters;
f. how best to deliver aged care services in a sustainable way, including through innovative models of care, increased use of technology, and investment in the aged care workforce and capital infrastructure;

In considering the terms of reference, Painaustralia makes the following recommendations:

Recommendations:

1. The Commission recognises the prevalence of pain among residents of aged care and its relationship to incidents of mistreatment and severe behaviours.
2. Targeted national pain programs are developed and implemented in residential and community aged care for staff, consumers and family, friends or representatives.
3. Access to best practice pain management that adopts a multidisciplinary approach is further considered to inform practice in aged care.
4. All staff in residential aged care facilities need to receive mandatory, high quality training in pain management and dementia care, including a biopsychosocial model of care and alternatives to physical and chemical restraint.
5. Embedding pain management across the new single quality standards as well as the new Aged Care Safety and Quality Commission to ensure providers are responsive to chronic pain across aged care.
6. Prioritised implementation of public reporting of aged care performance data including quality indicators for pain management.
7. Improved access to information and support for advance care planning for people living with chronic pain and their families and carers.
8. Pain management is prioritised in aged care funding and policy reform and practice. The ACFI is refocussed on paying for quality and cost-effective outcomes based on measures of performance.
9. Implementation of the National Strategic Action Plan on Pain Management to enhance access to best practice, community-based pain management services for older people living with chronic pain.
10. A new approach to pain management for rural and remote communities including the cultural needs of Aboriginal and Torres Strait Islander people.
11. Strengthen consumer protections for residents to help them exercise their choice and rights in care.

KEY ISSUES FOR CONSIDERATION:

Painaustralia has provided input to numerous aged care inquiries in recent years. The main issues we propose raising in the context of the Royal Commission are:

a. the quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response;

The prevalence of untreated pain in aged care

It is estimated up to 80% of aged care residents have chronic pain,[2,3] however more than half of residents (52%) in aged care facilities in Australia have a diagnosis of dementia while two in three (67%) require high-level care to manage behaviour.[4] This suggests a high proportion of people with chronic pain also have cognitive or communicative impairment and inability to report pain.

While chronic and acute pain is common among residents of aged care facilities, the evidence suggests that pain is misunderstood, poorly managed or undertreated, including the suboptimal use of analgesics.[5]

Evidence also shows that people with dementia in particular are living with pain and are being under-treated compared with cognitively intact persons, despite having similar levels of potentially painful disease.[6]

> *The grief my 91 year old dad and I have gone through while watching her [mum] approach death has been magnified by seeing her in pain. We've felt pretty ignored. My mum has experienced preventable pain when she can't advocate for herself. We felt the nurses waited for us and were never proactive themselves to manage her pain. The culture is pain is normal. Otherwise they provide good care. Her weight is steady at about 40 kilos, she has no pressure sores, the nursing home is clean, odour free, and staff are friendly. But I sincerely hope good proactive care, including assertive effective pain control at end of life becomes the norm. The use of palliative care services as experts should be more routine so families don't need to beg for it. The relationship between GP's, nursing homes and palliative care services needs reviewing so patients needs come first. Communication with families needs to be better.*
>
> *-carer of person in residential aged care*

In one study, pain was detected in just 31.5% of cognitively impaired residents compared to 61% of cognitively intact residents, despite both groups being equally afflicted with potentially painful disease.[7]

The prevalence of acute and chronic pain among those with dementia should be recognised as a significant factor in severe behavioural and psychological symptoms of dementia (BPSD), which may be caused by the expression of emotion or unmet need that the person with dementia cannot otherwise express, e.g. pain, frustration, fear.[8]

People living with dementia have shared stories of an aged care system unable to meet their needs with reports of incidences that span physical, psychological and sexual abuse; inappropriate use of restraints; unreported assaults; and people in extreme pain at end-of-life not having access to palliative care.[9]

Untreated or poorly treated chronic pain can perpetuate the pain condition and severely reduce function and quality of life. It impacts personal relationships and can have profound emotional and psychological ramifications.

For many people, feelings of anxiety, sadness, grief and anger related to pain can create a burden that is difficult to manage and may lead to the emergence of mental health problems. Major depression is the most common mental health condition associated with chronic pain, with rates of 30% to 40%, and there are also high rates of generalised anxiety disorder and post-traumatic stress disorder.[10]

These statistics are especially concerning in light of research by the National Ageing Research Institute that more than 50 percent of those living in aged care facilities have either anxiety or depression or both disorders, and just under 50 percent enter residential care with a pre-existing depressive condition.[11]

Cognitive or other communicative impairments of residents, inadequate training of aged care staff with day-to-day responsibilities for residents and workload that prevents adequate pain assessment are all barriers to effective treatment.[12] It can also lead to inappropriate use of physical or chemical restraints[13], misuse of pain medications and reliance on antidepressants.[14]

It is unsurprising that in 2016-17, the most common complaints made to the Aged Care Complaints Commission about residential care related to medication administration and management and falls prevention and post-fall management.[15]

Recommendation:

The Commission recognises the prevalence of pain among residents of aged care and its relationship to incidents of mistreatment and severe behaviours.

Quality of care

While ensuring access to appropriate staff levels is crucial to improve the quality of Australian aged care, the number of older Australians with chronic pain is significant, and the core business of both residential and home-based aged care services increasingly includes providing care to people living with chronic pain. It is critical that all aged care services have the capacity to provide quality care to people living with chronic pain, who are often frail and vulnerable, may have cognitive impairment and often have complex care needs.

I. Inadequate education and training of residential and community aged care staff leads to under-reporting of pain

Inadequate education and training of residential and community aged care staff is largely responsible for the under-reporting of pain in cognitively impaired residents—impacting some of the most vulnerable people in our society.

A recent survey found that 41% of care professionals reported having received no training in assessment of pain in people with dementia, while 90% of care professionals indicated that additional training in dementia would be beneficial.[16]

In its report *Encouraging Best Practice in Residential Aged Care Program*, the University of Wollongong states (p38):

"One of the issues in residential aged care is that clinicians with the most knowledge and expertise (registered nurses and general practitioners) have the least involvement in the day-to-day care of residents."[17]

The Australian Pain Society (APS) in its guidelines *Pain in Residential Aged Care Facilities- Management Strategies, 2nd Edition*, indicates that staff workloads may also be to blame, with a lack of time for adequate pain assessment on a regular basis. These Guidelines should be promoted across aged care as a useful resource that aids best practice pain management.

Education and training of staff is vital for the provision of high quality residential aged care, because when people with dementia or other cognitive impairment are in pain, although they are unable to tell anyone verbally, pain may trigger behavioural changes and any such changes should be investigated. These changes may also be observed by carers or family members.

> *As mum deteriorated her pain increased. She had multiple falls requiring hospital admission. There was inadequate supervision to prevent falls. She was only safe when she was unable to get up herself.*
> *- Carer of person in residential aged care*

It has been shown that Behavioural and Psychological Symptoms of Dementia (BPSD) are often an expression of emotion or unmet need (for example, pain)[18] and appropriate training would help to identify this.

> *Tried to implement allied health services to aid in treatment plan which wasn't received well. Some days was almost constantly reporting pain however current treatment routine wasn't adjusted*
> *-carer of person in residential aged care*

Aged care staff with day-to-day responsibilities for residents should have adequate knowledge and skills in pain assessment and management, including for people with dementia or other cognitive impairment.

This would be consistent with the Australian Government's National Safety and Quality Health Service Standards (Standard 1 Governance and quality improvement systems), which highlights the need for governance systems that set out clear policies, procedures and protocols for "implementing training in the assigned safety and quality roles and responsibilities."[19]

II. Insufficient education about best-practice pain management for aged care residents

Many older people believe that pain is a normal part of ageing and there is little potential for improvement. They also fear addiction to pain medications; they are concerned that pain may suggest worsening of disease; they are worried they will be seen as people who complain too much; and are also reluctant to seek help for fear of further functional dependence due to disease progression.[20]

Programs such as Seniors ADAPT by the University of Sydney and Pain Management Research Institute[21] have shown that age is not a factor in being able to improve function and quality of life, given education in best-practice pain management and the right support.

Residents who have sufficient physical and cognitive ability should have the opportunity to be actively involved in their own pain management. They should also be encouraged to develop a plan detailing their pain management wishes at end-of-life.

Another important aspect that has a major impact on resident health and quality of care is nutrition. As identified in the Nutrition Chapter (2) in the APS Guidelines, malnutrition and dehydration can directly affect pain experiences. Media reports and anecdotal consumer evidence suggests that there is insufficient attention paid to nutrition across aged care currently.

Training for food service staff needs to be implemented and monitored, as often those putting together the menu are not qualified to ensure the menu meets the nutritional needs of the residents. Allowances for better quality food and more staff to assist with meal times could reduce malnutrition and improve the pain experiences and quality of life of residents in aged care facilities, this can be cost effective considering the current cost of malnutrition. Taking a multidisciplinary approach to embedding areas like nutrition across aged care are crucial in improving outcomes.

Recommendation:

Targeted national pain programs are developed and implemented in residential and community aged care for staff, consumers and family, friends or representatives.

b. how best to deliver aged care services to:

i. the increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services;

Refocusing regulatory responses to Quality

In reviewing the incidences of abuse in aged care such as Oakden Nursing Home in South Australia, what has become clear is that developing industry standards and protocols is critical to ensure providers establish systems for aged care staff to conduct regular pain assessments for individual residents.

> *We were told there was a one-hour window around the designated time for any medication and that included pain meds. This was difficult for my dad as his pain increased very quickly when it was time for a new pain med. So after half an hour he was in heaps of pain. Towards end of life it became increasingly difficult as we would have to press the buzzer. It could take twenty minutes for someone to come then they would have to get a nurse which could take another half an hour. He was calling out 'please help me' 'make it stop' and it was so hard to help him. I had to continually ask for there to be a better pain management routine for him and it took days of asking before something happened.*
> *-Carer of person in residential aged care*

Currently no such standards and protocols are in place, and without them, there is no requirement for providers to implement this essential level of care for individuals. Notwithstanding acute pain from recent injury or surgery, the vast majority of cases of pain experienced by aged care residents are chronic pain. Chronic pain is usually considered as pain that has lasted beyond the time expected for healing following surgery, trauma or other condition—usually three months—then it may be considered a chronic illness.[22]

Despite the high prevalence of pain in our aged care facilities and the high rate of unmanaged pain, the Australian Aged Care Quality Agency's Accreditation Standards mention pain only in brief and in vague terms:

Standard 8.2 Pain management: All care recipients are as free as possible from pain.[23]

There is no requirement for a best-practice approach to care and no requirement to help the resident achieve better quality of life. The standard also fails to acknowledge the need for ongoing pain assessments or the need to identify pain in non-verbal patients.

A significant body of research has shown that medication alone is not an effective solution and that a holistic approach to pain management, known as multidisciplinary pain management, is the best way to minimise the impact of pain, reduce disability and improve function and wellbeing. This is a key recommendation of the National Pain Strategy.[24]

Recommendation:

Access to best practice pain management that adopts a multidisciplinary approach is further considered to inform practice in aged care.

The standard also fails to acknowledge the need for ongoing pain assessments for non-verbal residents. Cognitively intact residents may also face challenges in communicating pain, which could lead to under-reporting and under-treatment. If residents cannot express their pain and the workforce is not trained to manage Behavioural and Psychological Symptoms of Dementia (BPSD) then pain is not identified.

The current accreditation process for aged care facilities relies on self-assessment, with facilities inspected by the Australian Aged Care Quality Agency just once a year and assessors speaking to only a minimum of 10% of residents during inspections. Over 95% of facilities pass accreditation which seems extraordinary in light of genuine quality of care issues such as poor pain management. The risk of overlooking serious failures is therefore high, especially in the case of people with dementia or other cognitive impairment.

It is estimated that about half of people in aged care and about 80% of those with dementia are receiving psychotropic medications, often for management of BPSD. There is sound evidence to suggest that in some cases these medications have been prescribed inappropriately[25]

Our mother had delirium due to pain issues and staff (including GP) instead believed it was BPSD and overdosed her on antipsychotics instead of treating causes of pain
-carer of person in residential aged care

Professor Brian Draper, Conjoint Professor, School of Psychiatry UNSW, in a submission to the Senate Inquiry into the Care and Support of People with BPSD said:

"I am firmly of the view that this long term overuse of psychotropic drugs in residential care is largely indicative of a combination of a number of factors – poor facility design, poorly trained staff, inadequate numbers of staff and lack of suitable activity programs for residents. The behaviours being treated by drugs are exacerbated or indeed at times caused by these issues. Psychotropic drugs are used because GPs and residential care staff can see no other solution."

Recommendation:

All staff in residential aged care facilities need to receive mandatory, high quality training in pain management and dementia care, including a biopsychosocial model of care and alternatives to physical and chemical restraint.

Building consistency into quality indicators

Aged care in Australia is unique in that there are no nationally consistent and measured quality indicators. There is much to be learned in this regard from the public health system. Another example of how this might work is provided in the health care sector by the Australian Commission of Safety and Quality in Healthcare (ACSQHC), through the development and implementation of the National Safety and Quality Health Service (NSQHS) Standards.

Work is being done in this area through the development of single set of quality standards – the Aged Care Quality Standards, which will be implemented by 1 July 2019.[26]

However, it is important to note the Standards only establish the minimum acceptable level of service for accreditation, rather than providing any insight or guidance into whether a provider is delivering high quality care. While the single set of standards do take a more consumer directed approach, there are issues that need to be carefully considered to ensure that consumers aren't adversely impacted.

The aim to move to consumer directed care provisions can address some systemic issues, however this approach can be challenging in a regulatory sense. Market-based incentives do not work in a system that is operating at capacity or under supply. Many residents have no choice but to accept any facility available.

The roll out of a single set of quality indicators may assist in the comparison across residential aged care facilities resulting in greater transparency in relation to quality for consumers. There may also be a need to develop a more nuanced approach to Accreditation which would include whether a facility has met or exceeded the expected outcomes.

Painaustralia is also concerned that pain management is not being adequately addressed through the new standards. For instance, we are concerned to note that the new aged care quality standards do not acknowledge or consider the high risk and prevalence of chronic pain, despite nearly 80% of residents in residential aged care reporting chronic pain and despite the clear need for providers to have specialist capacity to manage pain appropriately.

> *Pain not assessed well, not assessed after an intervention, simply asking the person doesn't help, they know the staff are busy and don't want to bother them. Stronger drugs are always the option and an option that leaves them as zombies too.*
> *-carer of person in residential aged care*

We recognise that from the perspective of a service provider the concept of person-centeredness should mean the needs of each individual are understood and considered regardless of their unique situation. However, as the peak organisation representing and advocating for the needs of people with chronic pain, it is our role to ensure the needs of people with chronic pain are identified and supported. This is particularly significant around the discussion of what defines quality in aged care.

Recommendation:

Embedding pain management across the new single quality standards as well as the new Aged Care Safety and Quality Commission to ensure providers are responsive to chronic pain across aged care.

Removing barriers to accessing Palliative Care

In 2010–11, 75% of the 116,481 people aged at least 65 years who died in Australia had used aged care services in 12 months before their death[27]. The older a person was when they died, the more likely they were to have been accessing a service at the time of death.

There is evidence to suggest that many people, especially those with cognitive impairment, may experience poor quality care at the end of their lives. Issues can include inadequate pain management, inappropriate hospitalisation or medical intervention, and a lack of timely and appropriate consultation over their choices regarding end of life care.[28]

Nationally there were 231,500 permanent residents in Australia in 2014–15 with completed Aged Care Funding Instrument (ACFI) appraisals, yet only 1 in 25 of these indicated the need for palliative care.[29]

Managing pain at end-of-life is an important consideration. It requires much more than analgesic and other medication to manage pain. It needs to prevent suffering but should also take into account physical and psychological factors as well as spiritual and cultural beliefs and attitudes towards dying. For example, some people may not wish to receive a strong painkiller because of side-effects.

Clearly, right now our aged care services are not doing enough to provide recipients with access to appropriate and timely aged or palliative care. Ensuring the availability of high-quality palliative and end-of-life care services in aged care facilities and people's own homes, will enable more older Australians to have a good death, better support their families and carers during the dying and bereavement processes and facilitate the better allocation of scarce health resources. This should be a pivotal consideration for this Inquiry.

Mum has been palliative for 4 months now, and it's been a constant struggle to have her pain managed. She's in too much pain to move out of bed but the nurses didn't usually think she needed pain control. After regularly complaining I finally got palliative care involved, after weeks of them ignoring my request for a referral. The palliative care service devised a great plan, but the GP didn't like it so ignored it. My mother who says little will cry out in pain in touch, even with a patch on. The nurses were scared for being sued for administration of a PRN (pro re nata or as needed) dose of morphine.

The care manager requested this be given before care, we were told an audit showed it was being done, but day after day we'd find mum in pain. The Nursing home didn't feel they could advocate on mum's behalf as they are dependent on the visiting GP. Mum was moved into the 'autumn' room before Christmas, then moved out as she didn't die quickly enough. Her pain persisted. Still finding

When someone is dying, lets make them as comfortable as possible. Dying in pain for a human is inhumane.
-carer of person in residential aged care

These people are at the mercy of when medication is 'given' to them. When it takes an hour to get some this is too late and the pain has often escalated and the normal pain management is not enough. If it is given when needed it works well. But in our experience that rarely happened, and my dad just had to suck it up. We were also powerless to help him. There is certainly not enough staff, let alone nursing staff and doctors. If you are going to take away their ability to medicate themselves when needed, then at least find a way to lessen the time they have to wait.
-carer of person in residential aged care

Recommendation:

There should be improved access to information and support for advance care planning for people with chronic pain, their families and carers, as well as improved access to palliative care and pain management in aged care.

c. the future challenges and opportunities for delivering accessible, affordable and high-quality aged care services in Australia, including:

i. in the context of changing demographics and preferences, in particular people's desire to remain living at home as they age; and
ii. in remote, rural and regional Australia;

Changing aged care needs

The traditional image of aged care is often associated with residential care. While it is true that most of the expenditure is in the residential care sector, in fact most people stay independent and remain in their home, connected to family and community for the duration of their lives.

For some, home support and home care packages provide the level of support they need to maintain their independent living, with about two thirds of aged care consumers accessing basic support at home. Only a small proportion of senior Australians are accessing residential care at any point in time, yet nearly 70 per cent of aged care expenditure is on residential aged care.[30]

We need to pay more attention to changing consumer need and do more to support consumers in their preferred setting. One way to ensure that older Australians can be supported to live in their communities is to enable access to best practice pain management in the community.

Sadly, right now older people with chronic pain are left with two main options to get the best-practice treatment they should have. They are either forced to wait over a year to access multidisciplinary pain services and allied health through public hospitals or pay a premium for poor insurance coverage that largely neglects the needs of chronic pain patients. The result is that older people are often inappropriately pushed into seeking acute or residential aged care, a situation which often does not provide adequate pain management.

The evidence now shows that given chronic pain's individual effects, interdisciplinary assessment and treatment may produce the best results for people with the most severe and persistent pain problems. This can include non-opioid medications, special physical exercises, psychological approaches such as Cognitive Behaviour Therapy and techniques for how to self-manage and mitigate pain.

This holistic, patient-centred, multi modal approach to treatment is also a key recommendation of Painaustralia's National Pain Strategy,[31] and a critical component of the National Strategic Action Plan on Pain Management. If implemented, the Plan will be the world's first fully funded government response to comprehensively addressing the burden of pain, most urgently needed across aged care.

Recommendation:

Implementation of the National Strategic Action Plan on Pain Management to enhance access to best practice, community-based pain management services for older people living with chronic pain.

Meeting the needs of rural and remote Australians

Across the spectrum of health and welfare people in rural, regional and remote Australia experience worse health outcomes. They have less access to services and are exposed to increased health risks. Service access data reveals[32] that people in remote areas access MBS services at up to half the rate as people in metropolitan areas and the health workforce is under-represented.

The lack of places in rural and remote communities' results in more and more Australians with increasing community aged care needs accepting packages that do not cater for those needs on the basis that something is better than nothing.

Some health professional disciplines don't exist in many remote areas. In others, professions like optometrists, occupational therapists, dietitians and podiatrists are represented at between one fifth and one third the rate of metropolitan areas.[33] This is a vital gap that needs to be bridged, especially if we want older Australians to remain in their homes and communities.

For rural and remote aged care services to be delivered through a consumer demand driven model will require a significant change in emphasis in the current system of allocation of aged care places outside the major cities. Service models for remote and very remote communities must be flexible, small and integrated– for example as part of a Multi-Purpose Service combining hospital and aged care places funded jointly by Commonwealth and state/territory governments or as part of a community delivered service incorporating residential and community outreach aged care services.

Aboriginal and Torres Strait Islander people comprise 45% of the population in very remote communities. It is vital that the delivery of aged care services in remote and very remote Australia meets cultural needs and allows Aboriginal people to maintain their links to country and family. This also means a very different, flexible and responsive approach is necessary. This is a requirement to deliver both home based and residential aged care employing and supporting a culturally appropriate and culturally safe workforce.[34]

Recommendation:

A new approach to pain management for rural and remote communities including the cultural needs of Aboriginal and Torres Strait Islander people.

d. what the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe;

Public reporting of quality information

As highlighted in the many consumer stories that have surfaced over the course of the past year, people often make the decision to move a loved one into a residential care facility purely on the basis of marketing and promotional information, predominantly provided by service providers. For a person or their carer considering placement in a residential aged care facility, or considering a new home care package provider, there is no consistent information that can aid in this decision-making process, for instance whether a facility or provider has met or exceeded the expected outcomes.

Although the accreditation status of a residential aged care facility is publicly available, these documents are often difficult to interpret along with a lack of transparency as to how that relates to quality of care. Ultimately, it is vital that safety and quality mechanisms span consumer experience and quality of life within aged care services and that they are reported in a way that is both accessible and meaningful to consumers.

The lack of transparency across minimum quality indicators has an impact on people, many of whom enter residential aged care as they are unable to manage painful, chronic conditions like arthritis, back pain etc. in community-based settings. However, without any information to help support the decision making process, such as how a particular facility rates on delivery of pain management services, consumers are often making uninformed choices.

The Ministerial Review of National Aged Care Quality and Regulatory Processes, led by Kate Carnell and Robert Patterson[35] made many recommendations including a star rated system for publicly available performance reporting across residential aged care facilities, as well as many other recommendations that can significantly improve on the current state of aged care quality and regulatory processes, and which should be implemented as a matter of priority.

Providing public information on aged care quality will also empower people, their families and carers and build accountability to the end user into the system. This must include indicators on vital areas of aged care service delivery such as pain management.

Recommendation:

Prioritised implementation of public reporting of aged care performance data.

e. how best to deliver aged care services in a sustainable way, including through innovative models of care, increased use of technology, and investment in the aged care workforce and capital infrastructure;

Fixing Aged care's funding model

Residential aged care in Australia is predominantly funded by the Commonwealth Government through tax revenue with some finance coming from other levels of government and user co-contributions. Funding for each individual resident's care needs is determined by the ACFI with residents receiving a subsidy paying directly to the residential aged care provider.

The sum paid to the residential aged care provider is dependent upon the extent of the resident's care needs, with the ACFI used to determine the total amount of the subsidy in three areas: Activities of Daily Living (ADL), Behavioural Supplements, and Complex Health Care supplements.

However, a recent evaluation of the tool notes it is 'no longer fit for purpose'.[36] Firstly, the ACFI subsidy level is not related to the factors that determine the need for care. This is a fundamental flaw in the ACFI as it inevitably leads to negative consequences where providers are rewarded for admitting higher subsidy residents who will be relatively less expensive to care for.

Professor Kathy Eagar, who led the research team, from the Australian Health Services Research Institute based at the University of Wollongong notes that the ACFI in fact provides 'perverse incentives' to providers[37], in effect rewarding them to keep elderly residents more dependent on care.

"A person who can't walk, is completely bedbound and who has a wound ulcer is very different to look after than a person who's mobile with a wound ulcer. And yet the ACFI treats those two items as though they're independent of each other."[38]

Most significantly, funding freezes to the ACFI in 2016, have resulted in the reduction of subsidy for the complex health care supplement which particularly impacts high-needs residents with complicated pain-management regimes. This has led to the removal of essential pain management services such as necessary physiotherapy and palliative care and diminished the capacity of the sector to provide appropriate levels of pain management in aged care.

Despite the recommendations of the University of Wollongong report,[39] the ACFI remains unchanged, compounding the issues faced by residents of aged care every day. It is vital the Commission consider the impact of the current aged care funding mechanisms on the safety and quality outcomes of care.

Recommendation:

Pain management is prioritised in aged care funding and policy reform and practice. The ACFI is refocussed on paying for quality and cost-effective outcomes based on measures of performance.

f. how to ensure that aged care services are person centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care related matters;

Empowered consumers and carers at the centre of aged care

Aged care in Australia remains one of the few services where consumers are not routinely engaged as part of the quality assessment process. On the contrary, current safety and quality systems have created outcomes where we see multiple reports of consumers indicating they are fearful of complaining or making negative comments about service quality because they fear retribution on their loved ones and have limited options to access alternative care.

> *It's been a very stressful nightmare. Polite requests, repeated meetings and even the first visit from palliative care weren't enough. You shouldn't need to threaten ministerial complaints that eventually made the nursing home stress out about bad press during a Royal Commission to get effective pain management*
> *-carer of person in residential aged care*

Aged care in Australia needs to put consumers at the front and centre of service delivery, to match consumer expectations across nearly every other service sector in the country. We also need to empower consumers to have choice over the setting of their aged care services.

More and more consumers are now looking to age in place, with demand for home care packages and community based aged care far exceeding current supply. Building awareness of pain and its management is central to ensuring that consumers can be supported to self-manage their pain.

If we are to achieve an aged care system that supports people to live in the community for as long as possible, then it is also important to recognise that carers are an essential part of the equation. Thirty six percent of all carers are over the age of 65 and most are caring for a partner,[40] however right now there is no emphasis on education and training programs that enable carers and informal support to provide essential community-based care such as holistic pain management.

Recommendation:

Strengthen consumer protections for residents to help them exercise their choice and rights in care.

CONCLUSION

While access to pain management is acknowledged globally as a fundamental human right and the Australian Government recommends best-practice care for aged care residents, Australia's aged care facilities are falling woefully short of effective pain care.

A significant number of residents have pain that is under-treated and are suffering unnecessarily (particularly those with dementia or other cognitive impairment), something that could be avoided through appropriate workforce education and training and adequate regulatory reform of the accreditation and funding system.

Leadership at a national level that prioritises a multidisciplinary, industry-wide approach will be essential to address these issues. It should include an Aged Care Safety and Quality Framework that supports quality of life. This will be achieved with best-practice pain management, along with appropriate education and training of staff (particularly in the identification of non-verbal signs of pain); appropriate funding that meets the needs of each aged care recipient; appropriate reporting policies and protocols; and education for aged and community care residents, their families and carers with sufficient capacity to self-manage their pain where appropriate.

We hope our submission provides the Commission with the impetus to prioritise pain management as an important element of aged care. As Commissioner Richard Tracey noted in his opening remarks, we have a generational opportunity to create an aged care environment that affords dignity to the older and frail- some of the most vulnerable people in our society. Appropriate pain management in aged care will go a long way in providing that dignity.

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