We are now in the final 6 months of the HALT project. It is so encouraging to see the results coming together and to review what has been achieved over the last two and a half years.

In April, Fleur presented preliminary results from the project at the Alzheimer’s Disease International conference in Hungary which received very positive feedback and great interest particularly regarding the nurse education.

In July we will present an update on the project and further results at the Alzheimer’s Association International Conference in Toronto and in the next newsletter I hope to be able to share more exciting results with you.

I have been visiting all HALT facilities and chatting with champions and managers about their experiences during the project, things they’ve found positive, and suggestions for future initiatives. A number of common themes emerged from these conversations and I have chosen one of these issues to ‘spotlight’ in this newsletter. The majority of champions identified pain management as one of the most effective strategies for responding to challenging behaviours. This feedback from champions clearly confirms the well-known fact that pain is underdiagnosed and undertreated in people with dementia (see page 2).

If at any time there is feedback about the project that you would like to share with me, please do so! Email me at t.holmes@unsw.edu.au

As always, if you would like to follow the latest from the DCRCs and keep up to date on dementia-related research and news, follow us on Facebook, Twitter and LinkedIn.

Best wishes,

Tiffany Jessop (HALT coordinator)
SPOTLIGHT ON PAIN

The risk of both dementia and pain increases with age. A large proportion of people with dementia experience pain, yet they report pain less and fewer are treated for pain than people without dementia of the same age.

There is a misconception that people with dementia do not experience pain due to changes in their brain. However, studies have shown through functional MRI imaging that the same patterns of pain-associated brain activity are present in people with dementia as those who are cognitively intact (Cole, et al, 2006).

What is true is that as dementia progresses, people find it more difficult to recognise pain and to verbally communicate this with carers. Many non-verbal signs are useful in detecting pain in people with dementia.

The American Geriatric Society Panel on Persistent Pain in Older Persons established a list of behaviours and non-verbal signs that may indicate pain and should be investigated further (see Table).

Failure to diagnose and treat pain can lead to behavioural symptoms, poorer quality of life, depression, decreased mobility, inappropriate use of antipsychotics and undue suffering.

Clinicians should work with family members to identify if pain is present, assess severity and then implement an appropriate management plan.

A number of pain assessment scales have been developed for use in the residential care setting, such as the Pain in Advanced Dementia (PAINAD) tool (Warden, Hurley, & Volicer, 2003) and the Abbey Pain Scale (Abbey et al, 2004).

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### Table 3. Common Pain Behaviors in Cognitively Impaired Elderly Persons

<table>
<thead>
<tr>
<th>Facial expressions</th>
<th>Verbalizations, vocalizations</th>
<th>Body movements</th>
<th>Changes in interpersonal interactions</th>
<th>Changes in activity patterns or routines</th>
<th>Mental status changes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Slight frown; sad, frightened face</td>
<td>Sighing, moaning, groaning</td>
<td>Fidgeting</td>
<td>Aggressive, combative, resisting care</td>
<td>Refusing food, appetite change</td>
<td>Crying or tears</td>
</tr>
<tr>
<td>Grimacing, wrinkled forehead, closed or tightened eyes</td>
<td>Grunting, chanting, calling out</td>
<td>Increased pacing, rocking</td>
<td>Decreased social interactions</td>
<td>Increase in rest periods</td>
<td>Increased confusion</td>
</tr>
<tr>
<td>Any distorted expression</td>
<td>Noisy breathing</td>
<td>Restricted movement</td>
<td>Socially inappropriate, disruptive</td>
<td>Sleep, rest pattern changes</td>
<td>Irritability or distress</td>
</tr>
<tr>
<td>Rapid blinking</td>
<td>Asking for help</td>
<td>Gait or mobility changes</td>
<td>Withdrawn</td>
<td>Sudden cessation of common routines</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Verbally abusive</td>
<td></td>
<td></td>
<td>Increased wandering</td>
<td></td>
</tr>
</tbody>
</table>

Note: Some patients demonstrate little or no specific behavior associated with severe pain.

Source: AGS Panel on Persistent Pain in Older Persons.
An update on mortality risk for people with dementia taking antipsychotics was recently published#. This study compared the mortality risk between medication users (antipsychotic monotherapy) and non-users as well as those taking either an anti-depressant or valproic acid (Epilim). The findings confirmed that the greatest risk was associated with haloperidol.

The absolute mortality risk of using risperidone, compared to matched non-users, was 3.7%. Translated into ‘Number Needed to Harm’ (NNH), treatment with risperidone was associated with 1 death per every 27 people taking this medication, only just better than haloperidol at 26.

Evaluating data related to the risks of antipsychotic use in people with dementia is challenging. This poses challenges to clinicians considering prescribing medications, who need to weigh the published risks and benefits and clinical recommendations. This study reinforces the need to prescribe antipsychotics with great caution and review regularly both for efficacy and side-effects.


WHAT ARE CHAMPIONS SAYING ABOUT THE PROJECT?

Below are some comments made by HALT Champions during feedback sessions. Overwhelmingly Champions have been positive about the project both in terms of outcomes for participating residents and also the level of knowledge and awareness about the issue of inappropriate prescribing and promoting person centred care.

“When we first took (the residents) off the medication they were more alert, walking better, they didn’t look drugged out and it was nice; (resident) was able to have more of a conversation rather than just sitting in a chair. It was really positive.”

“I think you need to be there for the resident not for yourself. We’re not here for us, we’re here for the residents and everything you do is with them in mind. It may not always make out job easier, sometimes in a lot of cases it makes our job harder, but if that’s always at the forefront of everything you do. You’d want to do anything for them.”

“The case conference was a real eye opener, when you get the whole team on the same page because we all know little bits about people but when you all get together its very powerful.” - talking about strategies to facilitate person centred care.
Allan Shell – Academic GP

I joined the Dementia Collaborative Research Centre (DCRC) in 2009, as an Academic GP and UNSW Visiting Fellow, and soon became involved in general practice based research and “knowledge translation” teaching. Most of my work has involved projects that were supported by Alzheimer’s Australia, through research grant-based funding, within the great environment of the DCRC and its capable and knowledgeable team of research fellows.

As a long time GP, with private practice and hospital experience, I found the new post-graduate research and education experience to be highly rewarding. As with the HALT project, there was the opportunity to interview and provide detailing to other GPs, and often present them with added knowledge around the complex topic of dementia. It is also gratifying to know that a number of the GPs who were involved in the HALT project have made positive changes to their prescribing habits based on their experience with this project.

Over the past 4 years, I have also been a Project Lead in a national program – ‘The timely diagnosis and management of dementia in general practice”- together with the DTSC at La Trobe University. This workshop-based program was developed with a number of specialist colleagues, supported by the DCRC’s Professor Henry Brodaty, to provide for an excellent learning experience on dementia for GPs. This program has been successfully presented in all States, in both rural and regional centres, and continues to do so. And, it has been converted into an e-learning module, with internet access linked through the DCRC website at: www.dementiaresearch.org.au

WHAT ARE FAMILIES SAYING ABOUT THE PROJECT?

It’s always very encouraging and inspiring to hear positive feedback from the family members of our participants. Here are some comments from the wife of a participant who, at commencement of the project was not able to walk and used to be pushed in a water chair.

“I thank God every day that HALT came into my life at the right time to support my battles to stop the antipsychotic medication.”

“Everybody comments on his WALKING ability including visitors who knew him before.”

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