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Specialist residential dementia care for people with severe and persistent behaviours: A ten-year retrospective review

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Very severe behavioural and psychological symptoms of dementia (BPSD) have low prevalence but disproportionately poor outcomes for persons with dementia, others and systems of care, including inappropriate use of medication, tenuous accommodation, poor quality of life and increased costs. The Australian Government has established new Special Dementia Care Programmes (SDCPs) to provide interim care for up to 12 months for those with severe and persistent BPSD unsuitable for mainstream aged care. This 10-year retrospective review describes environmental design, governance, clinical processes, characteristics and outcomes for 80 residents of a similar-aged care mental health partnership SDCP. A key finding was that average length of stay was slightly over 12 months. All surviving residents except one were able to be transferred to mainstream aged care services. Doses of regular and PRN antipsychotic and anxiolytic medications were significantly reduced. SDCPs may have the potential to improve care and outcomes for this group of vulnerable older people.

KEYWORDS

aged, behavioral symptoms, dementia, nursing homes, retrospective studies

1 | INTRODUCTION

In Australia, there are approximately 459,000 people living with dementia (PLWD). This number is calculated to rise to 1,076,000 by 2058 in the absence of effective disease-modifying treatment.[1,2] Behaviours and psychological symptoms of dementia (BPSD) occur in up to 90% of PLWD, with greater frequency as the disease progresses.[3,4] BPSD includes a heterogeneous range of symptoms including disturbance of affect, perception and thought, with clinical presentations of delusions, hallucinations and other 'behaviours of excess' such as anxiety, agitation, aggression or disinhibition, and 'behaviours of omission', including apathy and depression.[3,5]

While BPSD is ubiquitous, it is estimated that less than 10% of Australians living with dementia will manifest aggression considered unmanageable in mainstream care services, and only approximately 1% will manifest very severe BPSD.[6] Severity of behaviour is a relative concept and may be applied to any behaviour that is perceived as creating difficulty for self, carers or others.[7] However, when defining severe BPSD, clinical consensus focusses on the impact of behaviours, particularly those involving physical and/or verbal aggression that threaten the safety of the person with dementia, others in their environment or property, and frequency and duration of the behaviours.[5,6,8]

Severe BPSD is also associated with tenuous accommodation arrangements, more frequent transfer to acute care [8] and inappropriate or prolonged use of psychotropic medication.[5,9] For others who experience severe BPSD, there can be significant distress, poor quality of life for family, work stress for staff and increased overall costs of care.[8]

In response to calls that mainstream aged care is unable to provide appropriate and safe care for this group, in 2016

the Australian Government Department of Health announced the creation of 35, 8- to 12-bed Specialist Dementia Care Programs (SDCP) across Australia's 31 Primary Health Networks.[10] The primary goal of SDCPs is to provide specialist accommodation and management for PLWD who are unsuitable for mainstream aged care due to the severity or persistent nature of BPSD, where behaviours are not primarily due to an acute condition. SDCPs are charged with *'stabilising and reducing the person's symptoms over time with the aim of enabling transition to a less intensive care setting'* (p.1) [11]. SDCPs are expected to provide an interim service of up to 12 months (depending on individuals' needs) and work in partnership with geriatric and psychogeriatric services.

Foundational work by the Faculty of Psychiatry of Old Age, Royal Australian and New Zealand College of Psychiatrists,[8,12] underpinned New South Wales Health (NSW Health) policy and subsequent development of two SDCPs as a partnership between Australian Government–funded residential aged care providers and the NSW Ministry of Health. One SDCP, opened in 2007, is operated by HammondCare, an Australian not-for-profit aged care provider, and located in South-West Sydney. This SDCP has informed policy framework of new SDCP services. This review describes the HammondCare service, and results of a retrospective file audit of SDCP residents' demographic, functional and behavioural characteristics, medication use, length of stay and acute hospitalisation rates over the first ten years of operation, from 2007 to 2018.

Policy Impact

The model underpinning Australian Government funded special residential dementia programs that provide interim, specialist care with enhanced staffing levels has the potential to provide better outcomes for people living with severe behavioural and psychological symptoms of dementia and reduce potentially inappropriate medication usage.

Practice Impact

People with severe BPSD are acknowledged as clinically difficult to manage and frequently inappropriate for mainstream residential care. Interim residential care programs with enhanced staffing and access to specialist support have the potential to improve resident outcomes, including reduction of potentially inappropriate psychotropic medication use and increase in successful transition to mainstream care.

1.1 | SDCP service description

The SDCP functions to provide interim, specialist accommodation and care for PLWD with behaviours unable to be managed under usual care arrangements, due to their severity or persistence and lack of response to previous psychosocial management and appropriate medication. The SDCP aims to develop strategies to manage behaviours and subsequently facilitate transfer to suitable mainstream aged care services that best meet residents' physical, social, behavioural and health-care needs.

The SDCP has two components: a specifically designed, 8-place domestic-style residential cottage, known as 'Linden', and an up to 8-place 'transition out' program that supports PLWD transitioning to mainstream aged care and the staff that will take over their care.

Figure 1 shows the co-location of the SDCP within a larger, 75-bed dementia-specific nursing home. The floor plan illustrates key dementia design features that provide a small, low-stimulus, homely and enabling environment, including clear visual access to promote wayfinding for residents and ease of surveillance by staff, a domestic-style kitchen where all food is prepared and a safe garden with 24/7 access.[13] Each resident is accommodated in a private bedroom with an en suite bathroom, and families are encouraged to personalise bedrooms. Linden has a ninth bedroom, which is not used for new admissions but can be accessed while a resident is transitioning to mainstream care or if a transition fails, to avoid transfer to an acute setting. Usual aged care staffing levels are enhanced through mental health 'top-up' funding. For 8 residents, there are 2 care staff (assistant in nursing or personal care assistant level) on duty at all times. A psychogeriatric experienced registered nurse (RN) unit manager is present during business hours, and RN support is available through the co-located nursing home after hours. There are a 3-day-per-week old-age psychologist, access to allied health staff, and a consultant psychogeriatrician, who monitors the progress of residents at weekly team meetings. Residents have their own general practitioner (GP). Care staff are employed to work in the co-located care home and self-select to work in the SDCP. All care staff are multi-skilled, providing all personal care, recreational activity, cooking, personal laundry and housework, and being involved in the generation and implementation of behavioural care strategies.

1.2 | Governance, admission and discharge

The SDCP is overseen by a joint HammondCare-NSW Ministry of Health Clinical Advisory Committee that monitors admission, discharge and management processes within the SDCP.

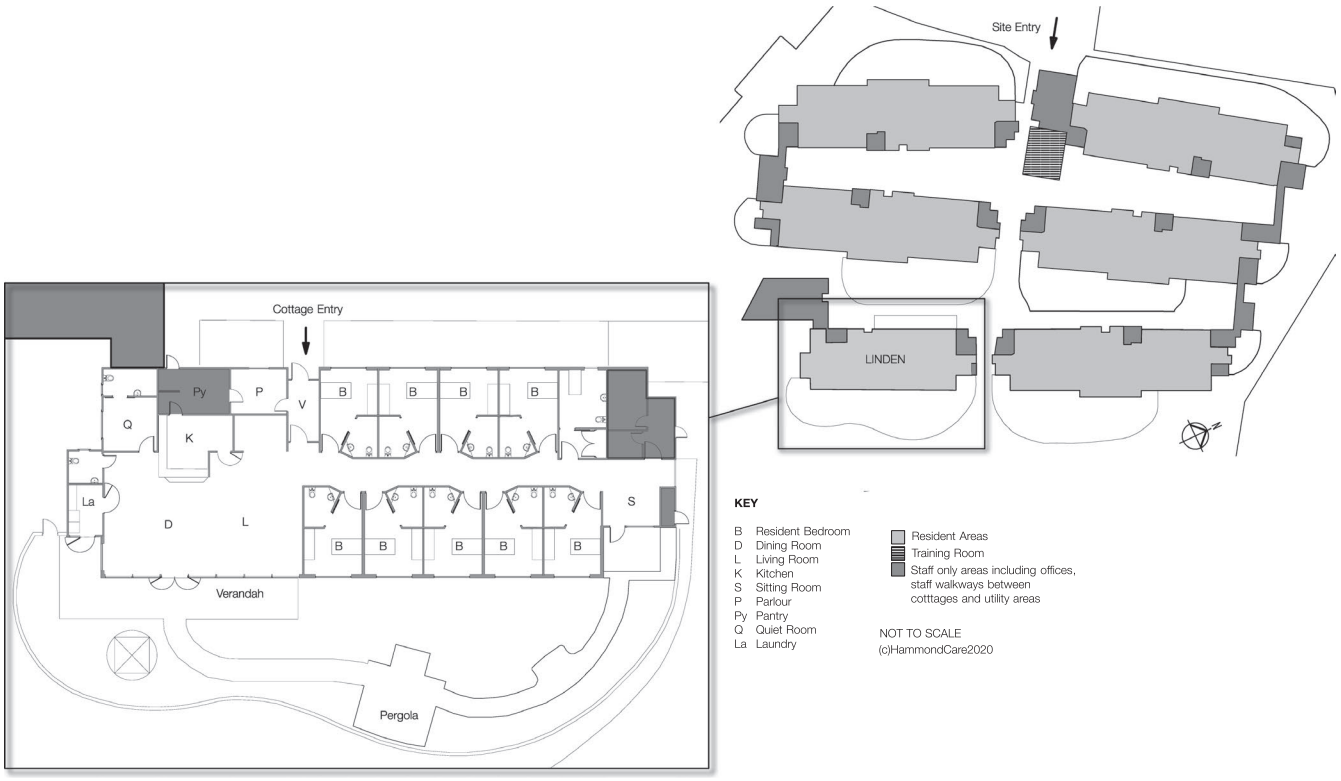

FIGURE 1 Floor plan of Linden SDCP, and site plan showing location within a larger dementia-specific nursing home. Image adapted to show spatial relationships of construction. Reproduced with permission of the copyright owner

Admission requires Aged Care Assessment Team (ACAT) residential care approval. The waiting list for admission is held by psychogeriatric services within the NSW Local Health District. Potential admissions are reviewed by the SDCP manager or psychologist and one Linden care staff for suitability, which is determined on presenting behaviours and fit with the prevailing social milieu. Common behaviours precipitating admission include unpredictability of physical and/or verbal aggression, abusiveness towards staff or other residents, sexual disinhibition, high levels of agitation, very low frustration tolerance, delusions or psychotic behaviour. Residents must be ambulant. Discharge is planned at weekly team meetings, and the 'transition out' program includes trials of short periods in other cottages of the co-located nursing home, which are used to inform readiness for discharge.

2 | METHODS

2.1 | Study design and data sources

The study design was a retrospective file audit of all extant Aged Care Client Records (ACCRs), organisational records relating to length of stay or hospitalisation, and medication charts of residents admitted to Linden SDCP from November 2007 to December 2018. An *a priori* list of resident characteristics of interest was generated and is reported below. Records were manually extracted and entered into an Excel spreadsheet. Missing data were excluded from interpretation for any given characteristic.

All data were extracted and de-identified by a data custodian before being provided to the researchers involved in the current study. The study was approved by St Vincent's Hospital Sydney HREC 2019/ETH00182.

2.2 | Measures

Measures of resident demographics, health and behavioural characteristics described and analysed for the present study were as follows:

- *Demographic characteristics:* age at entry into the SDCP; gender; type of dementia; location prior to entry to the SDCP.
- *Medical/health characteristics:* length of stay (LoS); number and average length of hospitalisations during SDCP stay; number of repeat admissions to the SDCP; location/destination of resident following discharge.
- *Medication information:* total converted regular and maximum total PRN prescribed antipsychotics (converted to *mg* chlorpromazine); total converted regular and PRN

prescribed anxiolytics (converted to *mg* diazepam); total converted regular and PRN prescribed opiates (converted to *mg* oral morphine); total prescribed *mg* paracetamol.[14-16]

- *Functional characteristics:* performance on the Resource Utilisation Groups-Activities of Daily Living (RUG-ADL) [17] ; performance on the total score of the Health of the Nation Outcome Scales 65+ (HoNOS 65+) [18] and the specific subscales of 'Physical illness or disability problems' and 'Problems with activities of daily living'; performance on the 'Carer dependency', 'Communication', 'Physical', 'Self-help skills' and 'Social interaction' subscales of the Care Planning Assessment Tool (CPAT).[19]
- *Behaviour characteristics:* performance on the Cohen-Mansfield Agitation Inventory (CMAI) [20] ; performance on the 'Behavioural disturbance' subscale of the HoNOS 65+; performance on the 'Behaviour', 'Confusion' and 'Psychiatric' subscales of the CPAT.

2.3 | Statistical analyses

Descriptive statistics were generated to characterise the demographic and health-related characteristics. Stable characteristics (ie gender, dementia type) were only described for residents on their first admission at the SDCP. The demographic characteristics of age and location prior to admission were described for every admission to the SDCP. Health characteristics, length of stay in the SDCP, average number of hospitalisations, average length of hospitalisations and discharge destination, were described for only residents who had either been moved out of the SDCP or who had died.

To analyse changes in the demographic and specific health characteristics of residents over time, residents were clustered into three groups based on the time of their entry into the SDCP: those who entered in 2007-2010, 2011-2014 and 2015-2018. Analysis of variance (ANOVA) was used to assess changes across these periods for characteristics of age, length of stay at the SDCP, length of hospitalisations and function as measured by the RUG-ADL. Pearson's chi-square was used to assess change in gender balance in the SDCP over these periods.

Paired Wilcoxon signed-rank tests were used to compare select functional and behaviour measures from the time of admission into the SDCP to the time of discharge or death. Paired Wilcoxon signed-rank tests were also used to compare changes to classes of medications for just those residents who were prescribed medications on admission. McNemar's chi-square was used to compare the frequency of residents prescribed a class of medication at admission to the frequency of residents prescribed that same class of medication at discharge. Measures and medications were considered to represent either admission or discharge characteristics if they occurred within 90 days of either a residents' admission to or discharge from the SDCP.

Results of data extraction were reviewed for credibility and checking of unexpected results was undertaken via discussion with the SDCP manager and psychologist, both of whom have been employed since the inception of the SDCP.[21]

3 | RESULTS

Since the SDCP commencement on 30 December 2018, 80 individuals have been admitted. Aged Care Client Records were not available for 19 residents who were discharged over 7 years ago, due to the destruction of ACCRs following the expiration of the mandatory health record retention period.

3.1 | Demographics

Available demographic data are described in Table 1. Overall, more men have been admitted, comprising 70.2% of all admissions. Comparing data on male and female admissions between 2007-2010, 2011-2014 and 2015-2018 demonstrates that cohorts have become significantly 'more male', χ^2 (2, N = 77) = 6.6, P = 0.04. Mean age on first admission for all admissions was 72.3 years, and there was no significant change in age at admission across all 3 time periods. Mean length of stay (LoS) was 433.9 days, and there was no significant change in LoS across all 3 time periods.

Nearly a third of dementia diagnoses (30.3%) were unspecified. Most residents were admitted from hospital (66.3%). Location of residents prior to hospital was not available. A smaller proportion were admitted directly from an aged care home (25.0%). Only 2.5% of all admissions were from a private home. Most residents were discharged to an aged care home: 64.4% to a dementia-specific home and 6.9% to a general aged care home. One-quarter (24.7%) of residents died while in the SDCP.

3.2 | Rates of admission to hospital

Of the 73 residents who have left the SDCP (discharged or died), 25 (34%) had been admitted to an acute hospital on 41 occasions. There were 30 hospital admissions (73%) for acute medical reasons, 8 (19%) for an exacerbation of behavioural symptoms, 2 (5%) for management of delirium and 1 (2%) for an acute psychiatric condition. The average length of stay for each hospital admission was 34.7 days (range: 1-171) with an average of 1.6 (range: 1-4) admissions. The remaining 48 residents were not hospitalised during their SDCP stay. There was no was no

TABLE 1 Demographic and diagnostic characteristics on admission and discharge from the Specialist Dementia Care Program (SDCP)

	Sample	n	%	Mean (SD)	Range
Total number of residents	80				
Current SDCP residents at time of analysis	7				
Number of repeat admissions	3				
Residents admitted 2007-2010	31				
Residents admitted 2011-2014	29				
Residents admitted 2015-2018	20				
Demographic characteristics					
Age at entry (years)	79 (1 missing)			72.25 (8.21)	56-88
Number of males	77 (3 repeat admissions)	54	70.2%		
Location prior to SDCP admission	80				
Aged care home		20	25.0%		
Hospital		53	66.3%		
Aged care mental health unit		4	5.0%		
Private home		2	2.5%		
Psychiatric unit		1	1.3%		
Dementia type	76 (1 missing, 3 repeat admissions)				
Dementia type unspecified		23	30.3%		
Alzheimer's disease		17	22.4%		
Mixed dementia		12	15.8%		
Vascular dementia		10	13.2%		
Alcohol-related dementia		6	7.9%		
Frontotemporal dementia		3	4.0%		
Younger onset dementia		3	4.0%		
Lewy body disease		1	1.3%		
Parkinson's related dementia		1	1.3%		
Hospitalisation					
Average number of hospitalisations during stay	73 (7 current); 25 have record of hospitalisation			0.6 (31.22)	0-4
Average time in hospital per admission (days)	73 (7 current); 25 have record of hospitalisation			11.4 (31.22)	0-171
Discharge characteristics					
Length of stay at SDCP (days)	73 (7 current)			433.9 (382.78)	7-2088
Discharge destination	73 (7 current)				
Dementia-specific nursing home for ambulant residents without major BPSD		17	23.3%		
Dementia-specific nursing home for ambulant residents with BPSD		13	17.8%		
Dementia-specific nursing home for non-ambulant residents with or without BPSD, who require palliation		17	23.3%		
Other nursing home (type not specified)		5	6.9%		
Private home		2	2.7%		
Hospital		1	1.4%		
Died		18	24.7%		

TABLE 2 Change in dose of prescribed regular and PRN antipsychotic, anxiolytic, opiate and paracetamol medications. Only residents prescribed with relevant medication at admission included

	n	Admission mean (SD)	Admission median	Discharge mean (SD)	Discharge median	*W*	*P*	Cohen's D
Regular antipsychotics (mg chlorpromazine)	44	195.5 (165.2)	162.5	109.7 (120.6)	100.0	527.0	<0.001*	0.6
PRN antipsychotics (mg chlorpromazine)	18	100.0 (67.0)	100.0	34.7 (41.3)	25.0	76.5	0.004*	0.8
Regular anxiolytics (mg diazepam)	17	20.4 (46.8)	5.0	4.5 (4.3)	5.0	87.0	0.03*	0.3
PRN anxiolytics (mg diazepam)	10	25.3 (22.7)	13.75	12.8 (25.0)	0.0	36.0	0.01*	0.8
Regular opiates (mg oral morphine)	4	50.9 (67.9)	23.75	11.6 (19.2)	3.1	3.0	0.4	0.5
PRN opiates (mg oral morphine)	3	2.7 (0.6)	3.0	1.7 (1.6)	2.1	1.0	1.0	0.6
Paracetamol (mg)	16	3125.0 (806.2)	3000.0	2311.9 (1249.1)	3000.0	41.0	0.03*	0.6

[a]*$p<0.05$, **$p<0.01$, etc.

significant change in hospital LoS across the admission periods of 2007-2010, 2011-2014 and 2015-2018.

3.3 | Behavioural characteristics

Residents did not significantly change in their performance from admission to discharge on any subscale of the CMAI, nor on the 'Behaviour', 'Confusion' and 'Psychiatric' subscales of the CPAT. Residents demonstrated a significant reduction in behaviour from assessment to discharge as measured by the 'Behavioural disturbance' subscale of the HoNOS 65+, $W = 112.0$, $P = .02$.

3.4 | Functional characteristics

Residents did not significantly change in their performance from admission to discharge on the total score of the HoNOS 65+, the 'Problems with activities of daily living' subscale of the HoNOS 65+ or the functional scales of the CPAT. Residents demonstrated a significant increase in frailty as measured by both the 'Physical illness or disability' subscale of the HoNOS 65+, $W = 13.5$, $P = .05$, and the total score of the RUG-ADL, $W = 14.0$, $P = .009$.

3.5 | Changes in antipsychotic, anxiolytic and analgesic medication

Residents prescribed regular antipsychotics, PRN antipsychotics, regular anxiolytics, PRN anxiolytics or paracetamol at intake demonstrated a significant reduction in their total daily dose of these medications at discharge ($W = 527.0$, $P < .001$; $W = 76.5$, $P = .004$; $W = 87.0$, $P = .03$; $W = 36.0$, $P = .01$; $W = 41.0$, $P = .03$, respectively). Changes in all other medications were not significant.

The proportion of residents who were prescribed a regular antipsychotic at admission (85%) was significantly higher at admission than discharge (62%), χ^2 (2, $N = 52$) = 10.3, $P = .001$. Changes in the proportion of all other medications from admission to discharge were not significant. Results are presented in Table 2.

4 | DISCUSSION

This study describes the environment, staffing and governance of a SDCP, as well as resident characteristics and changes over 10 years, from 2008 to 2018.

The residents of the SDCP described in this study are consistent with descriptors of tier 6, 'dementia with very severe BPSD', as presented in the 7-tiered service model for BPSD[6] : that is, residents on average are a decade younger than mainstream residential care admissions, more men than women are admitted, and the group is generally more physically mobile and has severe behaviours that are frequently aggressive in nature, such that '*residential staff or family are unable to cope despite assistance from other services*' (p.233). Linden provides an environment recommended in the 7-tier model, providing secure, accessible outdoor spaces; greater staff-resident ratios than commonly found in mainstream residential aged care; and multi-disciplinary staff with mental health expertise. Of the 62 admissions who did not die during their stay in the SDCP, only 3 were unable to be successfully transferred to mainstream aged care.

Average LoS in the SDCP was slightly over 12 months, fulfilling the transitional aim of the SDCP. Transition occurred despite the lack of overt evidence of reduction in behavioural scores. The reasons for this appear complex. Behaviours in some residents may be relatively intractable but staff may develop techniques to lessen the impact of behaviours, without reducing frequency or type of behaviours per se. We showed a significant increase in frailty between admission and discharge, which may have bearing on lessening impact of behaviours, particularly physical aggression. Other program elements may have contributed to successful transition, including graded exposure of the resident to the environment they were transitioning to, support and training of staff of the receiving mainstream service in specific management strategies, and moving to a residential environment similar to the SDCP, incorporating a small, home-like environment with a flexible, resident-centred model of care and access 24/7 to the outdoors. Potentially, success of transition to mainstream care for this particular group may be predicated on the accessibility of a variety of suitable 'step-down' residential care environments that provide similar freedom of movement, staff with specialist dementia training and ease of access to support from specialist geriatric or psychogeriatric services when required.

Efforts to reduce potentially sedating psychotropic medication have been largely successful and follow recommendations of Australian Clinical Dementia Guidelines.[22] Anecdotally, the SDCP RN manager and psychologist both reported that reducing psychotropics resulted in residents being more alert and engaged but cautioned that medication needs to be carefully titrated to improve alertness, but not exacerbate behaviours. We were not able to demonstrate improvements in function, though staff report some significant improvements during their stay in the SDCP in self-care (eg eating) and interest in surroundings, other people or activities such as music.

This review indicates that Linden is managing the intended target group for SDCPs. However, policy expectations that behavioural symptoms will be reduced in SDCPs may be unrealistic.

4.1 | Limitations and strengths

As a retrospective observational study using extant clinical records, major limitations were an incomplete data set and correspondingly small numbers of observations for many of the analyses. As such, many of the comparisons, especially for measures of behaviour, were not sufficiently powered to find differences over time. Strengths were that majority of data were recorded by one person, a clinical psychologist, and results were validated through discussion with senior clinical staff who have been employed since the inception of Linden.

5 | CONCLUSIONS

The HammondCare SDCP 'Linden' has been operational for over ten years, providing specialist accommodation and behavioural management for older people with very severe behaviour, who are considered unsuitable for usually aged care arrangements. Linden demonstrates that this model can support a majority of residents with very severe BPSD to be transferred to mainstream aged care after approximately 12 months. In 2019, the first of the proposed new Australian Government Aged Care SDCP programs commenced, influenced in part by this NSW Health-Australian Government Aged Care partnership model. Future research should focus on confirmation of the impact of the SDCP model and management strategies on resident behaviour as well as whole-of-system service utilisation for this vulnerable group of people.

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CONFLICT OF INTEREST

Meredith Gresham was an employee of HammondCare during the conduct of this review. Thomas Morris, Sabrina Chao, Catriona Lorang and Colm Cunningham are current employees of HammondCare.

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