

Occupational Therapy Australia Ltd
Oncology and Palliative Care Special Interest Group
Senate Standing Committee on Community Affairs: Inquiry into Palliative Care in Australia

Response to questions on notice from the committee hearing into palliative care held on Wednesday 4th July 2012.

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There are no OT's currently working within the paediatric palliative care service based at the Royal Children's Hospital, Melbourne.

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Case Study 1: _____, a 22 year old male with metastatic alveolar rhabdomyosarcoma

Medical history:

Alveolar rhabdomyosarcoma diagnosed in 2008

- prolonged course of chemotherapy
- radiotherapy to right hemithorax to the pleura followed by whole brain abdominal radiotherapy (completed April 2010)
- restaging CT chest, abdomen and pelvis 13/7/2010 – no disease recurrence
- restaging CT chest, abdomen and pelvis 19/10/2010 – suspicious for recurrent disease
- CT 07/1/11 – pleural/ peritoneal disease progression
- radiotherapy base of skull metastasis 01/2011 + chemotherapy

History of presenting complaint:

Admitted to an acute inpatient specialist hospital from local hospital on 13/4/11 with chest tightness and acute onset bilateral leg weakness and sensory loss (right worse than left). Unable to weight bear. Clinically evident T4 spinal cord compression on background of T4 vertebral compression fracture. Received 20Gy in 8 fractions radiotherapy to T4 spine with some improved lower limb strength and able to pivot transfer. Bowel and bladder function remained intact.

Social History:

- Lives with supportive parents and 2 teenage brothers
- Prior to admission he was in second year university and had a very activity social life. He particularly enjoyed playing football on weekend, going to see live music at local pubs with his friends, skateboarding with his brothers, spending time with his girlfriend and driving the car which he had recently purchased.

identified the following goals during his admission:

- Return home
- Remain as independent as possible – including to be independent with all transfers, wheelchair mobility and personal activities of daily living (showering, dressing, toileting)
- Shower daily as he reported this was an important part of his “normal life” and also assisted greatly with pain relief
- Remain in own bed so that able to sleep next to his girlfriend
- Socialise with family and friends which included seeing bands with his friends, going to the skate park with his brothers and going for drives in his car (as a passenger)

OT interventions

To achieve _____ goals, the following interventions were required:

Functional assessment and rehabilitation

Given reduced bilateral lower limb strength and sensation, _____ was only safe to pivot transfer. Transfers (bed, chair, toilet, car and commode) and wheelchair mobility were practiced daily during his admission. A range of adaptive equipment was trialled to assist with transfers and

education was provided regarding safety and strategies to assist with personal activities of daily living.

Home set-up

Issues Identified:

- Access: front step which would be unable to independently negotiate in wheelchair
- Shower recess: lip at entrance which would not be able to manage given he is only able to pivot transfer
- Toilet transfers: using rail in situ on ward for support
- Seating: couch at home unsuitable due to low seat and armrests and no leg support

Solutions:

Discussions with and his family were had regarding solutions to address issues with home set-up with having strong ideas about what he deemed acceptable and what was “definitely not an option.” The following was negotiated and agreed upon:

- portable ramp for front step
- self-propelled wheelchair
- self-propelled commode
- over-toilet frame (for use until rail installed)
- electric recliner chair
- Roho cushion
- bedstick
- bed wedge

was referred to OT at the local hospital for a home assessment to arrange wedge into shower recess, hand-held shower and installation of rail in toilet.

Pressure care

- Education provided regarding pressure care strategies
- declined using an air mattress
- Roho cushion arranged for use in wheelchair and recliner armchair

Discharge outcomes:

Discharged home 14 days post admission at which time he was independent with

- all transfers
- self-propelling commode
- wheelchair mobility inside his house and community
- showering, dressing and toileting

Most importantly, was able to participate in age appropriate social activities with friends and family which was a high priority for him.

remained at home for 4 weeks before he elected to be admitted to an inpatient palliative care unit for end of life care.

Issues:

1. *had to sponge-wash for 5 weeks once home due to delay in home modifications which meant his goal of showering daily was not achieved during this time. This was due to:*

- Community OT home assessment unable to be conducted for 2 weeks post discharge
- Local council took 3 weeks to arrange modifications

2. *Financial cost to family*

- Applying for government funding through the SWEP program was inappropriate given was a) not eligible given his limited prognosis and b) even if he was eligible, he would likely die or have altered needs before the lengthy application process was complete
- Family had to pay for
 - home modifications through the local council. As council services are means tested and based on fathers income, the cost was almost equivalent to what a private company would charge
 - hire of electric armchair as the community palliative care service did not deem it as an “essential” item
 - purchase of bed wedge as unable to hire through private equipment supplier
- mother ceased work as required full-time care

3. *Carer stress*

- Confusion regarding equipment supply and long term funding arrangements
- Equipment had to be arranged through the local hospital and a private supplier which caused the family confusion as to “who was paying for what” and where to return it when no longer required
- Community Palliative Care(CPC) team would not confirm ongoing funding arrangements until they had assessed the patient at home causing additional stress about long term costs

4. *Appropriate prescription of equipment*

- Despite OT assessment and equipment recommendations, CPC wanted to substitute inappropriate items which were available within their limited stock. OT had to advocate strongly for CPC to fund hire of specialist equipment through a local private provider

Case Study 2: , a 34 year old woman with Glioblastoma Multiforme (GBM)

Social

- Lives with husband and 2 young daughters (8yo and 11yo)
- Husband self employed but finding it increasingly harder to continue working whilst caring for his wife, also completing course via night school (eventually ceased) which led to financial difficulties

Past history

- Several craniotomies for debulking of tumour (i.e. removal of tumour bulk from inside skull to relieve pressure, not curative treatment)
- Nil remarkable other medical history
- Unable to have any further radiotherapy, chemotherapy or neurosurgery to tumour

Presenting issues

- Poor short term memory
- Decreasing mobility, unsteady on feet
- Seizures that are increasing in frequency. Daughters have rung an ambulance on more than one occasion when home alone with Mum whilst seizures occurred.
- Severe headaches

priorities during admission

- Using her time purposefully, bored doing nothing, not acknowledging her limited prognosis which was difficult for her husband
- Return home
- Help daughters with school projects
- Do some cooking at home
- Go on outings with her sister and parents

OT priorities

- Establish baseline level of function – physically and cognitively
- Increase endurance and independence with transfers and bed mobility
- Close liaison with husband regarding his capacity to cope with at home
- Close liaison with physio who was reviewing need for gait aids

OT interventions

- Personal Activities of Daily living assessment (i.e. assessment of capacity to manage showering, dressing, toileting – taking patient to the shower and getting them to do as much as they can for themselves and then assisting physically or cognitively with strategies to manage self care)
 - required a shower stool to sit due to fatigue which was placed at optimum height to enable less effortful and safer sit – stand
- Cognitive assessment – both standardised assessment and functional assessment (see above). Assessment demonstrated better visual than verbal memory, capacity to follow

only 2 step instructions and reduced capacity to comprehend her deterioration and the impact of this deterioration on her capacity to manage at home

- Formal assessment informed how the rest of the team communicated instructions to (i.e. only single or 2 step instructions, use of written diary to remember visitors, plans for the day etc. Physio to give 2 step instructions when teaching how to use a 4 wheeled walker (unsteady on her feet)
- Domestic Activities of Daily Living Assessment: came to the OT kitchen and made biscuits for her daughters and husband. She chose to freeze the remaining dough and took it home on day leave where she cooked the remaining biscuits with her daughters (and husband's supervision). These were taken to school for Christmas party
 - During cooking of biscuits OT reinforced safe use of gait aid around kitchen, reinforced safe transfers (sit to stand), "in context" education around fatigue management, functional cognitive assessment, boosted self esteem because she assisting daughters with school project, giving something back to family instead of just being a patient, able to be a mum.
- Home assessment: was taken to home with OT to establish feasibility of discharge, to provide opportunity for husband to speak openly away from hospital environment.

Issues

- *Narrow toilet, inward opening door:* difficulty backing in with 4 wheel walker and uncontrolled stand-to-sit onto toilet seat. wanted to close the toilet door which posed a falls risk if she fell as she would obstruct another's entry into the toilet. also had very limited warning about the need to get to the toilet and walked slowly. Falls are often caused by people rushing to get to the toilet in time
Outcome – provision of commode to be used by bedside, husband prepared to empty this, able to adjust it to height that made sit to stand safer, enabled access to toilet quickly during the night. NB: husband had talked about making modifications and pulling walls out to enlarge the toilet. One of the unique skills that palliative care OTs employ is a sensitivity about managing discussions like these, timing of conversations around deterioration, judicious use of monies (both patient and government funded) as arranging for major modifications when someone may have a prognosis of only 3-4 weeks is disruptive and expensive and if completed may remain unused and a constant reminder of what has transpired
- *Shower recess, no equipment:*
Outcome – provision of shower stool for safety and to manage fatigue. OT referred to local council for removal of shower screen door, replaced with shower curtain, installation of grab rail as felt more confident stepping in and out of the shower with something stable to grab hold of, installation of hand shower to enable adjustment of water temperature while she was sitting on the stool
- *Kitchen:* While was unable to attend to most of the cooking now she still wanted to assist where possible
Outcome – provision of kitchen trolley on wheels, 2 shelves, which enabled to carry plates to the table, cups of tea, etc. Part independence is highly valued as capacity to participate diminishes

- *Outings:* mobilised on a 4 wheel walker but was unsteady and could not walk distances. She wanted to go shopping and purchase Christmas presents for family.
- *Outcome:* Provision of a wheelchair enabled to go on outings (Christmas shopping, coffee with her twin sister), the park with her daughters when out on day leave. Training around safe wheelchair use provided to husband and sister
- *Access:* husband was a practical handy man and had built a ramp at the front door to eliminate the front steps

spent her remaining months between the palliative care unit and her home, being readmitted for symptom management (seizures, headaches, decreasing mobility) or for respite for her husband. The children visited regularly and sometimes stayed in her room overnight. She died peacefully in the palliative care unit. Although this was not her wish, her husband and daughters were not able to cope with her dying at home.

Case Study 3: _____, a 41 year old man with metastatic bowel cancer and cervical spinal metastases causing high level quadriplegia

Admitted to an inpatient Palliative Care Unit at for symptom management and assessment

Presenting issues

- Metastatic bowel cancer causing catastrophic functional decline
- Incomplete C5 quadriplegia caused by cancer spreading to cervical spine eroding bone and spinal cord.
- Otherwise stable disease, some small bowel metastases and liver metastases
- Unable to move legs or support trunk in sitting
- Confined to hospital bed
- Some minor arm movements, very weak grip on left side, slightly better on right

goals during admission (4 month admission):

Occupational Therapy

- Ultimate goal of returning home to his family (wife and 2 young daughters primary school age)
- All minor goals centred around _____ strong desire to return home even if only temporarily
- Holding a cup/fork to be able to feed self independently
- Being able to press the call buzzer for nurse assistance whilst in the palliative care unit
- Pressure care management
- Wheelchair mobility if possible

OT interventions

- Joint Allied Health Assessment with Occupational Therapist, Physiotherapist and Social Worker.
- OT Upper Limb assessment- _____ was unable to use the standard nurse call buzzer system due to his decreased strength and movement in his hand and upper limbs. Set up Adapted Nurse Call Buzzer Switch to allow _____ to call the nurses on his own. Also adapted cutlery and cup to enable _____ to independently feed/drink himself
- Pressure Care Assessment with Nursing Staff. Arranged Low air low mattress replacement system given _____ high risk of developing pressure ulcers. Pressure ulcers can develop very quickly and progress through to muscle and bone in a matter of weeks if not managed effectively. Not only does this place a tremendous financial burden on the health service, it is painful and distressing for the patient and carers. Education provided for his family on pressure relieving strategies in hospital bed/mattress.
- Wheelchair trial was unsuccessful due to pain whilst using hoist sling. After much discussion, decided to aim for discharge home with 'Bed Based Care'. Multiple interventions with the nursing staff and family to teach basics of bed based care (manual handling, catheter care, bowel care, etc)
- Involvement in multiple family meetings to discuss overall care plan

- Arranged complex equipment hire, hospital bed, air mattress replacement system, over bed table, adapted doorbell call system, slide sheet, urinal bottle etc
- Home Assessment x2 to assess feasibility of the environment for equipment access and secondly to trial equipment at home prior to discharge

Discharge outcomes:

- Discharge home to family with a lot of support from community palliative care service (Mercy West Palliative Care Service) and family
- A home death was discussed with [redacted] and this was his wish as long as his children were not adversely affected

[redacted] was discharged home in late October 2009 and spent 3 weeks at home with bed based care. During this time the OT was in constant contact with his wife to discuss how he was managing and to trouble shoot many small issues that arose during his time at home. [redacted] died peacefully at home approximately 3 weeks after his discharge from the palliative care unit.

Issues:

- Prior to admission to the Palliative Care Unit, [redacted] was assessed for inpatient rehabilitation at the Victorian Spinal Cord Service (Royal Talbot Rehab Facility) but deemed “inappropriate” because his spinal injury was “not traumatic”. Being non traumatic largely relates to the fact that he does not have compensation from the Transport Accident Commission or Work cover. Traumatic injury spinal patients are able to access expensive equipment, home modifications and care services. [redacted] was not eligible for this.
- [redacted] had a number of Quality of Life goals once he returned home which were not able to be explored given the community palliative care service did not have any Allied Health staff including OT. These included wanting to try wheelchair mobility again as his pain had significantly improved after he went home. The OT from the palliative care unit attended to these goals as best as possible over the telephone but was unable to meet this need due to lack of an OT staff member at the palliative care community service.
- [redacted] was at home for just 3 weeks after discharge from hospital. If he had have stayed alive for longer than 30 days after his discharge his family would be responsible for the cost of all of his equipment (for an indefinite period of time). His equipment costs were approximately \$200 per week. Given [redacted] was the main bread winner in the family and had not worked since his diagnosis they were already experiencing significant financial burden.

Case Study 4: _____, a 59 year old man with metastatic prostate cancer

Admission 1: 18th May 2010 to tertiary palliative care unit

Referral source: Oncologist from private hospital. _____, a self employed plumber had presented to a private emergency department with a sudden decrease in mobility. He was diagnosed with metastatic spinal cord compression and underwent emergency spinal surgery (fusion and laminectomy T 4/5/6/7), chemotherapy and radiotherapy. He was transferred to a private rehabilitation facility but had a recurrence of metastatic spinal cord compression with severe pain. He was transferred back to the acute private hospital for radiotherapy and pain management. He was then transferred to a palliative care unit for respite, while renovations to facilitate access to his home were completed.

Presenting issues

- Paraplegia
- AKPS 40
- Pain 8/10. Exacerbated by movement.
- Poor sleep and fatigue.
- Mild confusion – confusion rating scale – 2.
- Two Stage II pressure injuries.
- Pathological crush fractures of L1 and L2
- Metastases to liver and lung - asymptomatic
- Anal sphincter tone reduced– oozing incontinence. Major factor affecting discharge
→ Paraplegic spinal bowel regime implemented.
- Suprapubic catheter for urethral obstruction.
- Impaired cognition - lacked insight into physical abilities. Had difficulty planning tasks.
- Angry and verbally abusive at times.

goals during admission:

Occupational Therapy

- Return home
- Be as independent as possible
- Manage pain
- Get control of bowels
- Partner to manage care safely
- Achieve a comfortable seating solution in a wheelchair
- Pressure injury management

Physiotherapy

- Improve sitting balance
- Roll in bed with reduced pain

OT interventions

- Completed initial assessment. Established goals with _____ and his partner.
- Joint OT and physiotherapy assessment of function.
- Trial of commode with tilt in space to access shower with reduced pain.
- Trial of two different wheelchairs with tilt in space.

- Trial of different pressure relieving cushions to
 - Provide adequate pressure care when sitting.
 - Support sitting posture
- Provided with ROHO Quattro pressure reducing cushion.
- Worked with physio and nursing team to educate partner on hoist transfers, bed based care and safe work practices to minimise risk of injury to partner.
- Provided education and support to partner about all aspects of care, the importance of self care and likely financial implications for care.
- Provided advocacy for and his partner, as many members of the team felt his partner could not manage care at home.
- Participated in a family meeting to address aspects of care and discharge planning.
- Home assessment to review works in progress (\$12,000 bathroom renovation and \$3,000 ramp – privately funded, as required immediately to enable discharge), arranged while in rehabilitation.
- Referrals to community services (including community OT).
- Sourcing of specialised equipment and applications to V.A&E.P (now S.W.E.P) for re-issue and new equipment
- Worked with and his partner to encourage a shared vision of how it would be to receive care at home/ establish realistic expectations.

Discharge outcomes:

- Optimised seating in a manual wheelchair with tilt in space (tolerance for sitting in wheelchair built up to 4 hours). able to self-propel short distances.
- Provision of a pressure relieving cushion.
- ↑
- Prevented further breakdown of pressure injuries.
- Home modifications completed.
- Equipment totalling \$290.00 per week (\$90.00 per week paid by the community palliative care service); 4 function hospital bed with cot sides and self help pole, pressure relieving mattress replacement system, over-bed table, hoist, princess/tub chair, wheelchair, ROHO, slide sheets and commode with tilt in space.
- Partner to provide care (took 13 weeks long service leave) with support of community palliative care service and RDNS – shared care achieving 1 x 1hour visit each day (Partner providing care 23 hours per day). Partner to purchase private nursing service occasionally - given the expense. Partner utilising small number of informal supports to assist with care.
- OT at community health service accepted referral for review of pressure care and follow-up of applications for funding of equipment.

was discharged home on 20th June 2010. He was visited by the OT at home the day after discharge to review set up and provide in home education to his partner. was cared for at home by his partner for 12 months, after which he was admitted to another palliative care unit and died a short time later. The community OT was successful in obtaining some equipment through S.W.E.P. This included a motorised wheelchair which enabled to access the local library and coffee shop. The financial consequences of having cared for at home were significant for his partner.

Case Study 5: , a 69 year old man with metastatic prostate cancer

Admission 1: Jan 31 2011 to a tertiary palliative care unit

Referral source: Oncologist from private hospital and reviewed by Palliative Care consultant and deemed “too frail to go home directly.” Transferred to a palliative care unit for restorative care/gentle rehabilitation

Presenting issues

- Cutaneous metastases over pubis/lower abdomen/penis –requiring dressings
- Anal sphincter tone reduced, rectum filled with soft faeces, perineum soiled with faeces – oozing incontinence. Major factor affecting discharge
 - Paraplegic spinal bowel regime implemented but incontinence persisted
- Pain : moderate in leg: responded well to medication
- Permanent R nephrostomy,
- Non functioning obstructed L kidney → moderate renal failure
- Suprapubic catheter for urethral obstruction
- Lumbo-sacral plexopathy – R foot drop affecting gait.
- Small lung metastases – asymptomatic
- Intact cognition

goals during admission:

Occupational Therapy

- Return home
- Be as independent as possible
- Be able to sit straight in his chair – had been sitting asymmetrically for 18 months since his nephrostomy, leaning through L arm
- ↑ concentration, manage fatigue
- “Do something useful,” return to work if this was at all possible
- “Get control of bowels”

Physiotherapy

- Improve LL strength
- Improve mobility to walk with SPS
- Improve confidence in transfers & mobility

OT interventions

- Completed Occupational Self Assessment (OSA) Standardised empirically developed self assessment tool which elicits patient identified goals and priorities for intervention
- Trialled different types of pressure relieving cushions to
 - provide adequate pressure care when sitting (risk of pressure ulcer development identified on admission – Braden score of 13)
 - Improve sitting posture: now able to sit symmetrically, read a book, eat more comfortably etc
 - Provided with ROHO Quattro pressure cushion (retails at ~\$850, hired public by hospital for first 4 weeks post discharge and then hire to go to family or through unassigned bed fund if possible)
- Optimise functional ability (self care & work)

- Worked with physio to teach and reinforce safe transfers from bed – chair, chair – standing
- Education around energy conservation to manage fatigue
- Provision of shower stool to reduce fatigue when showering, optimise safety. also used this to sit on when he needed to attend to his nephrostomy, leg bag for urine etc.
- Identification of work tasks still within his capacity. had assumed on admission that now he was receiving palliative care work was no longer an option. He was self employed and running his business with his son. He was encouraged to bring his lap top into work and education was provided about pacing/fatigue management that would enable to attend to simple work tasks via computer as able.
- Work with & his wife to identify barriers and facilitators to discharge home – confidence in ability to manage in everyday tasks, and faecal incontinence highlighted by both and his wife.

Discharge outcomes:

- ↑ confidence to mobilise (Ankle foot orthosis provided by PT to manage foot drop and trained in how to use a 4 wheel walker
- Sitting symmetrically, more comfortable, able to read for longer, eat more comfortably, interact with others
- Declined Occupational Therapy Home Assessment, but did take Roho cushion for home use
- Returned to work in family business post discharge

was not discharged straight home but first went to a local private hospital where he underwent surgery for development of a receiving colostomy. He experienced faecal incontinence through the duration of his admission and the colostomy resolved this issue
Discharged 17 March 2011

Admission 2: 10 June 2011, admitted from acute hospital
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Presenting issues

- Admitted to acute hospital following a fall on 07/06/2011 (legs ‘gave way’) Weakness in left leg & pain in both legs
MRI showed extensive vertebral metastases with some epidural extension of tumour L1, L3, Sacrum
↓↓ Confidence in left leg
- Pain on admission considered neuropathic & responded well to medication
- Rest In Bed”: 10 days post fall – weaker after this bed rest
- Increased oedema (R leg) → required larger Ankle Foot Orthosis from physiotherapy
Required assistance by one to help get L leg into bed
- Wife providing ↑ assistance with self care at home due to fatigue

- Mobility further impaired – short walks only with use of a wheelchair for longer distances.
- Discharged home 14/07/2011

goals during admission:

- do as much for himself for as long as possible both in regards to self care and work
- to not be a burden on his wife

OT interventions

- Trialling of assistive equipment/teaching techniques to help get his enlarged oedematous L leg into bed
- Review of R leg
- by Lymphoedema OT: lymphatic massage, wife trained in simple massage techniques which resulted in softening of tissues, ↓ R lower leg circumference
- Adjustment of Roho cushion: ↑ oedema in R leg had altered posture and capacity to sit upright. Cushion was altered to prevent him sliding forward in chair. Resulted in ability to sit upright again and ↓ pain
- Decreased leg strength and confidence now meant had to mobilise in a wheelchair – OT provided education about type of chair, safety, stairs, inclines, ramps.
- Revision of fatigue management strategies
- 2 OT Home Assessments were conducted: pre & post discharge
 1. taken out to home with OT in hospital car
 - Determined best access for which was achieved by use of portable external ramp (single step only) and small threshold ramp to eliminate lip of sliding door and enable smooth access into the house
 - practiced transfers in home environment and education provided to wife and (Wheelchair to chair, chair to wheelchair, wheelchair to bed, bed to wheelchair
 - practice of car transfers from wheelchair
 - Bed mobility remained effortful and a bed pole was trialled and enabled to independently get from lying to sitting. NB: this was extremely effortful but important to . Wife assisted getting his leg into bed when had insufficient strength to use the leg lifter
 - Provision of wheelchair, education on use within home environment/outings. Required gloves as skin on hands was fragile and pushing wheelchair damaged the skin as did banging hands on furniture as he wheeled past. Son and Granddaughter also present during Home Ax and explanations/education provided to them also
 - Reinforcement of strategies/back up for when function deteriorated or symptoms escalated.
 2. Post discharge review of how and his wife were managing. Getting from the palliative care unit to the car and then home during the first assessment had exhausted and his capacity to practice transfers was diminished

Discharge outcomes:

- Independent wheelchair mobility
- 4 WW for transfers only
- & wife apprehensive but wanting to try at home
- Provision of equipment & home set up to enable discharge
- Continuing to attend to work duties as able, more so by lap top at home now

Admission 3: 05 August 2011, admitted from home with functional decline. Died on 28 August

Presenting issues

- Hoist for all transfers, had not been getting out of bed at home
- ↑ fatigue
- Wheelchair for all mobility
- Short Term Memory Loss
- ↓ concentration
- Fungating pelvic tumour (Necrotic tissue breaks through skin surface)
- Spinal cord compression

OT interventions

- Joint assessment with physio to ascertain physical ability to transfer now – not possible. Trial with physiotherapist in tracking hoist (overhead gantry that supported his weight). Still not able to stand unsupported.
- aware he was deteriorating but still wondered if home was an option with additional equipment such as a hoist (some families do manage this). He came to the conclusion it would be too difficult for his wife because of deteriorating function and worsening symptoms (pelvic tumour oozing and requiring constant change of dressings).
- He continued to sit out of bed as he was able in a wheelchair with a pressure cushion and moved himself around on good days.
- Supportive counselling, identification of remaining priorities
 - Discussion around work, important for to leave a legacy for son
 - He had purposefully used the last 8 months to teach son how to run the family business more effectively,, hand over what he knew
 - continued to work until 2 weeks prior to his death via lap top and phone.
 - initiated reflective discussion about a life lived, wanting to have an ongoing contribution to society. (along with his wife) actively worked with the OT on a key note presentation to the national palliative care conference, August, Cairns, 2011 and his story was a key part of that presentation. He wanted people to understand the importance of continuing to live until you die, of being able to do as much for yourself for as long as possible. He gave permission for his story to be presented at conferences, undergrad lectures and other forums.

continued to deteriorate and died peacefully and comfortably on 28/8/11 in the palliative care unit.

Case Study 6: , a 76 year old woman with metastatic breast cancer

Referral source: Community palliative care service. had been cared for at home by her husband, who had injured his shoulder while assisting with her care. Her mobility had been declining and her admission to the palliative care unit was precipitated by her inability to transfer off the toilet, necessitating that her husband call the ambulance service to assist her off the toilet.

Presenting issues

- Left arm lymphoedema
- Multiple bony metastases (spine, shoulder and soft tissue)
- AKPS 40
- Pain at rest
- Impaired mobility
- Constipation
- Stage IV pressure injury on spine
- Stage II pressure injury on buttock
- Incontinent at times
- Fatigued
- Falls
- Husband has new injury to his shoulder, is tired and stressed.

priorities during admission

- Maintaining her mobility
- Being as independent as possible
- Being comfortable
- Discharge home
- Die at home if at all possible

OT priorities

- Establish baseline level of function.
- Maintain endurance and independence with transfers and bed mobility
- Support independence with personal care tasks
- Close liaison with husband regarding his capacity to cope with care at home
- Close liaison with physio
- Achieve adequate pressure care

OT interventions

- Initial Assessment to establish previous level of independence and home set-up.
- Personal Activities of Daily living assessment i.e. assessment of capacity to manage showering, dressing, toileting – taking patient to the shower and getting them to do as much as they can for themselves and then assisting physically with strategies to manage self care. required a shower chair to manage fatigue and her risk of falls.

- Provision of a pressure relieving cushion and modified seating to support pressure injury care and comfort when sitting out of bed. Implementation of other strategies to support pressure injury management.
- Implementation of a functional maintenance program to support [redacted] in maintaining or improving her independence with showering and her mobility.
- Family meeting to explore the capacity of [redacted] husband and her children to continue to assist with her care. During the family meeting [redacted] repeatedly expressed her wish to return home. However, because of his shoulder injury, [redacted] husband expressed that he was unable to continue to assist with her care. A decision was made to undertake an Aged Care Assessment (ACAS).

Shortly after the ACAS [redacted] deteriorated and she died peacefully in the palliative care unit.

Issues

[redacted] husband sustained his injury while assisting [redacted] with lifting her legs into bed. An occupational therapy home assessment some weeks prior to the admission would have reduced the risk of [redacted] husband sustaining injuries while providing care. It would have supported her independence and reduced the likelihood of [redacted] falling. Had intervention been provided earlier, [redacted] wish to remain at home may have been achieved. She may then have been admitted for end of life care. The ambulance callout and the ACAS might also have been avoided.

Equipment provision suggestions

Issues

1. Lack of equitable access to low cost or no cost equipment

Limited life expectancy often means palliative care patients are not considered eligible for the Victorian State-wide Equipment Program as the stated criteria is for 'people who have a permanent or long-term disability' (<http://swep.bhs.org.au/node/30>)

Unless someone has been an inpatient at a public hospital, there is no or limited financial support to contribute to hire costs.

Equipment suppliers vary considerably in their hire, purchase & delivery fees. Some rural and metropolitan areas have limited suppliers to choose from

High delivery and collection fees are frequently incurred by the family

2. Timeliness of prescription & supply

The SWEP application process may take months to years depending on the item being requested and many of our patients have died waiting.

There is an enormous variation between how each community palliative care (CPC) provider uses their unassigned bed fund e.g. some fund equipment, others use it for medications or limited equipment, some have time limits on available funds

There can be a wait for an OT assessment and subsequent prescription and provision of equipment for community based patients as very few CPC teams have OT's on staff. This shifts the onus of care to community health based OT's who have long waiting lists and may not have palliative care experience. In addition, they are required to see palliative care patients (though this does not always occur) as a high priority above clients who have already waited on the list a long time. Additionally, these services do not have ease of access to equipment and are also limited to using SWEP or private funding.

3. Cost

Supply of equipment essential for care of complex or debilitated patients within the home can easily accrue and often exceed \$200 in weekly hire fees.

This may be covered short term by a public hospital (30 days post discharge is DHS mandated agreement) and *may* then be assumed by a CPC (all or partial costs) OR the full cost/shortfall is absorbed by a family already experiencing significant emotional and financial strain.

Not all palliative care patients are in the terminal phase of care, therefore ongoing costs may need to be covered for an indeterminate amount of time.

4. Accurate assessment of need

Well meaning families and staff with no specialised knowledge of functional assessment and equipment prescription regularly suggest or arrange inappropriate equipment which may be unsafe or unnecessary. Furthermore, it can actually promote functional decline making it

harder for both patient and family/carers to manage and in some cases trigger readmission to acute services.

Criteria

Clearly there are a number of access and equipment supply and funding problems across the multitude of available health services. This is in addition to patients and families needing to use many services in order to have their needs met.

Any equipment system designed to address the needs of palliative patients and their families would include the following criteria:

- i. Assessment and prescription by trained, accredited health professionals
e.g. based on the SWEP or DVA prescriber model
- ii. Any administration would need to be simple with a low paperwork burden to prescribers
- iii. Equipment provision to patients and families needs to be low/no cost, easily accessible regardless of geographical location, offer a variety of items for any length of time required and ensure equipment is maintained and transported at no cost
e.g. based on Motor Neurone Disease equipment library model
(<https://mnd.asn.au/service-providers-mainmenu-153/equipment-service-mainmenu-159?task=view>)
([http://www.mndaust.asn.au/uploads/30227/ufiles/Submission disability care and support inquiry.pdf](http://www.mndaust.asn.au/uploads/30227/ufiles/Submission_disability_care_and_support_inquiry.pdf))

Possible solutions

1. DVA style national scheme with suitable suppliers contracted to provide equipment on a state wide basis. The benefits of this would be a national standard of service for administration, prescription, supply, maintenance and transport of equipment. This is a nationally tested model responsive to client and clinician need.

2. Refine the existing SWEP scheme with the addition of funding for a highly responsive team specifically to manage palliative patients based on the above criteria.

Either solution could also incorporate the use of the Australian Karnofsky Performance Scale (AKPS) as a tool to indicate level of functional decline and therefore level of equipment/funding required. These suggestions are a preliminary in nature and any equipment scheme would require substantial planning prior to implementation.

Appendix 1

The Australian Karnofsky Performance Status scale (AKPS) is a screening tool modified from the Karnofsky Performance Status scale (KPS). The original KPS is recognised as a gold standard measurement of functional status for hospitalised oncology populations. A study by Abernathy et al (2005) found the AKPS an appropriate tool for assessing inpatient and community palliative populations. It was found to have higher face validity than the original KPS and longitudinal test-retest reliability. It was also found to be more sensitive to detecting change in the lower end of the scale than the KPS.

Australia-modified Karnofsky Performance Status Scale (AKPS)

Score	Activity Descriptor
100	Normal; no complaints; no evidence of disease
90	Able to carry on normal activity; minor signs or symptoms
80	Normal activity with effort; some signs or symptoms of disease
70	Cares for self; unable to carry on normal activity or to do active work
60	Requires occasional assistance but is able to care for most of his needs
50	Requires considerable assistance and frequent medical care
40	In bed more than 50% of the time
30	Almost completely bedfast
20	Totally bedfast and requiring extensive nursing care by professionals and/or family
10	Comatose or barely arousable
0	Dead

References

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