

WESTMEAD

HEN study hatches best practice



Researcher, senior clinical dietitian Liz Parker (right) watches Westmead dietitian Danielle Doughty coach her patient in home enteral nutrition

A nutritional support service provided to patients in hospital and at home after discharge has been associated with improved patient outcomes and reduced healthcare costs.

However, a new study has found its method of delivery is inconsistent across the State, affecting approximately 7600 patients.

Home enteral nutrition, or HEN, refers to nutritional support for patients in the form of supplement drinks, thickened fluids, or special formulas delivered via a tube into the patient's stomach or small bowel, known as tube feeding.

A study by Westmead's senior clinical dietitian Liz Parker found the provision of HEN services are improved when overseen by a dietitian.

Research indicates the importance

of HEN through its association with improved health outcomes such as better immune function and wound healing, improved patient comfort, fewer hospital readmissions, and reduced healthcare costs, Ms Parker says.

"HEN reduces hospital stays," she says. "In particular, in the case of tube feeding because in the past patients who needed this had to stay in hospital. If they can be trained to do it at home, they can leave hospital earlier."

A patient might require HEN for various reasons. For example, they may not be able to meet their nutritional needs through diet alone; they may have trouble swallowing after a stroke or as a result of head and neck cancer; they might have a physical disability that affects their ability to eat and/or drink; or they may not be able to absorb

Director's desk



NURTURING A FERTILE FUTURE

Spring is a little way off but buds are appearing on the research tree and the education tree in western

Sydney. Let me point to them.

First, research is blossoming at Blacktown and Mount Druitt.

New academic appointments from Western Sydney University are finding their feet. Well done! And long may it continue.

At Auburn, the University of Notre Dame Australia is bringing its research and education to bear on local health problems.

The development of the new precinct at Westmead provides a wonderful opportunity to think freshly about what we want to do in education and research to aid clinical care, advance our knowledge, educate our future doctors, nurses and allied health professionals.

It means we need to plan buildings for education and research and work out how to best locate them in the new wards.

This reflects our desire to ensure the best arrangements for clinical care, research and education to work together.

We have lots of partners and immense help in this task.

The new education facilities in the lower level of the Westmead Hospital education block are

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PROFILE

Elizabeth's calling

Senior staff specialist at Westmead Hospital's Neurology Department and Huntington's Disease (HD) Service, Elizabeth McCusker, can remember the day in March 1993 that, after years of effort, the HD genetic abnormality was announced.

"My colleagues, and Robyn Kapp, CEO of Australian HD Association, NSW, telephoned and rejoiced, 'the cure must surely be close!'," Dr McCusker recalls.

More than 20 years on and, in spite of much collaboration and commitment from international HD researchers, patients and their families, a cure has not yet been found for the debilitating, hereditary neurodegenerative disease.

HD is caused by a gene mutation that

each child of an affected parent has a 50 per cent chance of inheriting.

Age of onset varies, but is typically in their forties. The disease causes involuntary movement and dementia, emotional and behavioural problems.

"It's disappointing that all these years have gone by and there's still no cure," Dr McCusker says.

"We know that people with HD have the genetic mutation from birth, but when, how, and why exactly does the disease start and progress?"

"On the horizon is the possibility of manipulating this genetic mutation by gene silencing, which would reduce the effect of the abnormal gene."

Dr McCusker's training in neurology included study at the University of Rochester in New York with the founder of the Huntington Study Group, Dr Ira Shoulson.

On return to Australia, she headed up the HD outpatient clinic at the former Lidcombe Hospital in 1988.

In 1995 she moved to Westmead Hospital and established the HD service that includes outreach multidisciplinary care.

In 2008 Associate Professor Clement Loy took over. Dr McCusker now concentrates on research.

"Our team has been involved in international and local drug trials, observational studies, as well as Westmead's own HD research projects," she says.

Director's desk continued

looking splendid, and they are spreading upstairs as well!

Nursing and allied health are developing research and education plans and agendas and are celebrating successes as new academics take up positions with us.

This has been a busy but satisfying year so far for us. We hope it continues to be so!

Emeritus Professor Stephen Leeder
 Director, Research & Education Network

"They have included participation as a research site for the landmark 10-year study of premanifest mutation carriers, Predict HD; the observational study COHORT; and the current observational study, ENROLL HD, which aims to recruit up to 20,000 participants as a means of searching for genetic modifiers, but also to enable trial-readiness for people at different disease stages.

"There is a very close-knit, international group of researchers and clinicians.

"It is compelling work.

"Care is better now but the hope is that we will progress to the ultimate cure."

This land is your land

Huntington's disease (HD) is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain.

It is the most common dementia in young people.

It deteriorates a person's physical and mental abilities during their prime working years and has no cure.

HD is known as the quintessential family disease because every child of a parent with HD has a 50/50 chance of carrying the faulty gene.

HD does not discriminate. It affects all

sexes, races and ethnic groups.

One May day in 1956, police in New Jersey, US stopped a skinny 43-year-old man wandering along the highway.

Assuming he was a vagrant, they thought his murmurings about being famous were mere hallucinations.

When they dialled his manager's phone number he gave them they discovered he was more than famous: Woody Guthrie was a legend.

Guthrie, who wrote *This Land Is Your Land* and more than 3000 folk songs, was suffering from Huntington's disease.

At the time the neurological disorder

was completely misunderstood.

He was hospitalised at a psychiatric institution, and though his family, friends and acolytes, including a 19-year-old Bob Dylan, visited him, a cone of silence descended on the time he spent in hospitals until his death at age 55.

Songwriters such as Dylan, Phil Ochs, Johnny Cash, Bruce Springsteen, Robert Hunter, Harry Chapin, John Mellencamp, Pete Seeger, Andy Irvine, Joe Strummer, Billy Bragg, Jerry Garcia, Jay Farrar, Bob Weir, Jeff Tweedy, Bob Childers, Sammy Walker and Tom Paxton have acknowledged Guthrie as a major influence.

Research Governance with Maggie Piper*



DEPARTMENT HEAD

It is important to note an investigator who is also head of department must obtain the signature of their manager. They cannot approve their own research in their department or have a subordinate sign off on behalf of their unit.

A facility requirement of Blacktown and Mount Druitt hospitals is for the general manager to sign as head of department.

SUPPORTING DEPARTMENT

Examples of supporting departments include pharmacy, pathology, medical imaging, medical records and treatment units providing care. The supporting department indicates the level of support ranging from providing within present resources to unable to provide support.

The only difference is WSLHD research governance obtains the signature of Westmead Hospital and Auburn Hospital head of department for radiology. A C-BIRD form needs to be presented to radiology at the time of submission to research governance.

References

Office of Health and Medical Research (OHMR):

<http://www.health.nsw.gov.au/ethics/Pages/faq-ssa.aspx>

NSW Ministry of Health:

Authorisation to commence human research in NSW Public Health Organisations PD2010_056

http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2010_056.pdf

Operations Manual: Research Governance Officers GL2010_015

http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/GL2010_015.pdf

Research Governance in NSW Public Health Organisations GL2011_001

http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/GL2011_001.pdf

* Maggie Piper is the Research Governance manager at the WSLHD Research & Education Network

One of the responsibilities of research governance is to ensure all investigators, heads of department and data custodians have signed the relevant declaration pages on the site specific assessment (SSA) form.

NSW Ministry of Health's *Authorisation to commence human research in NSW Public Health Organisations PD2010_056* states it is the responsibility of the principal investigator to:

- Obtain signatures of the relevant:
 - + Heads of department (or divisional directors) to whom each investigator at the site reports
 - + Heads of supporting department(s), providing support to the research; and
 - + Data custodian(s) for specific data collection held at WSLHD required to be accessed as a part of the research (if applicable)
- Discuss the proposed research project and its resource implications with the relevant head of departments
- Submit the SSA to research governance; and
- Conduct the study at the site.

Below are some pointers to assist with the submission.

INVESTIGATOR

To avoid confusion about what is meant by investigator for the purpose of submission to WSLHD it means research team members, which include doctors, clinical trial coordinators, research nurses and registrars conducting study activity at the WSLHD site.

Write This Way with Olivia Wroth*



WHEN LESS IS NOT MORE: FEWER v LESS

Communication is the main purpose of language, so fussing about the small details is often overkill, especially in general conversation and shop signs.

But when writing for grants and journals, take the time to make sure you use grammatically correct terminology and phrases.

This signifies your serious intention and careful approach, admirable qualities in researchers.

A source of irritation to the more pedantic reviewers of grants and articles is the incorrect use of "less" when "fewer" should be used.

An easy way to remember which to use is this: if you can count it, use "fewer"; if you can't count it, use "less".

For example, "You should eat fewer apples" but "You should eat less apple sauce".

Apples can be counted but apple sauce cannot.

Units of time, money, distance and weight are exceptions to this rule. For example, we say "less than \$20", not "fewer than \$20".

A related and less controversial confusion is "much" and "many".

We tend to use "many" with plural-count nouns, and "much" with mass nouns. So "many thanks" sounds more correct than the lesser used "much thanks".

I advise you to:

- a) Eat more apples instead of fewer
- b) Save your new-found grammar for your formal writing; and
- c) Avoid lecturing your friends about it.

Language is, after all, a human construct and you do not make friends by correcting people's grammar.

*Olivia Wroth is the medical and grant writing advisor to the WSLHD Research & Education Network. For help with your grant proposals and journal submissions, Olivia can be contacted at olivia@superscriptwriting.com.au or via the REN intranet

BLACKTOWN

Patients winners in national hospital evaluation

Blacktown Hospital is taking part in a first-of-its-kind in Australia, wide-reaching study into how management systems and processes affect hospital patients.

Director of Medical Services at Blacktown and Mount Druitt hospitals Dr Brett Gardiner predicts the research will result in better outcomes for patients.

"I think everyone will benefit from the study because it will give some understanding in this country as to the things we are doing from a management level to get better patient outcomes," Dr Gardiner says.

Deepening our Understanding of Quality in Australia (DUQuA) is an extension of similar research recently conducted in Europe (DUQuE), and is funded by the National Health and Medical Research Council.

More than 30 hospitals are participating nationally in the project which is investigating relationships between quality management systems, clinical processes and patient outcomes.

Jeffrey Braithwaite, professor of Health Systems Research at the Australian Institute of Health Innovation (AIHI) at Macquarie University is heading the research, supported by AIHI research fellow and lead researcher Dr Robyn Clay-Williams.

Prof Braithwaite says the investigation is important because of a growing interest in what and how quality improvement activities contribute to better care for hospital patients.

"Quality management systems are seen as integral to the

way modern organisations, including hospitals, are run," he says. "But do these hospital quality management systems benefit patients?"

The study focuses on treatment in three areas: stroke, hip fracture, and heart attack.

"Many patients suffer from these conditions, and hospitals have developed stringent guidelines for their management," Prof Braithwaite says.

Doctors and nurses are being interviewed about the quality management practices in their hospitals, and on their wards, as well completing surveys on the leadership and culture in their workplaces.

Patients are being asked how they have felt, and what they have observed, during their hospital stays.

Dr Gardiner says: "The researchers are coming at it from all different angles.

"They are trying to identify patterns where management processes and patient outcomes intersect in order to ascertain what is being done at a management level that results in better quality of care for our patients."

Presentation of findings is expected to begin later this year.



Dr Brett Gardiner

IP and Commercialisation with David Markwell*



The University of Sydney has recently appointed a new commercial theme leader for medicine who is based full-time at the Westmead precinct.

I am pleased to introduce Dr Nadia Pece-Barbara who will work closely with me.

This is an exciting step towards building a small team of managers to provide greater support for the commercialisation of intellectual property (IP) across the Westmead Hub.

Nadia comes with a breadth of experience including a PhD in immunology from the University of Toronto; post-doctoral research in developmental biology, cancer and genetics at the Lunenfeld-Tanenbaum Research Institute, Mount Sinai Hospital; 10 years' experience as a patent attorney in two top-tier firms in Sydney; and most recently as an IP and commercialisation manager at the University of Technology Sydney.

For research staff, this will provide a single point of engagement and further resources for intellectual property and commercialisation matters across Western Sydney Local Health District, the Westmead Institute for Medical Research, the Sydney Children's Hospital Network, and the University of Sydney.

Nadia is currently located in the Westmead Institute for Medical Research building where I will co-locate part-time.



Dr Nadia Pece-Barbara

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* David Markwell is the manager, IP and Commercialisation at the WSLHD Research & Education Network

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enough nutrition from their food and drinks because of bowel disease or surgery.

"HEN is a cost-effective, reliable way to treat patients who continue to need nutrition support after hospital discharge," Ms Parker says.

"However, our research shows it is better implemented, and meets more of the recommended guidelines, when overseen by a dietitian.

"Out of 59 public hospitals surveyed in NSW, only 12 hospitals reported having

a dietitian allocated to HEN.

"Hospitals with a HEN dietitian scored a higher rate of compliance with best-practice guidelines, compared to hospitals without a HEN dietitian."

If there is no coordination of HEN, when patients go home there's a greater risk of them being lost to follow-up, Ms Parker says.

"Also, having a dedicated clinician to coordinate the service means there's just one point of contact for patients."

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www.wslhd.health.nsw.gov.au/Research---Education