

## **The Winston Churchill Memorial Trust of Australia**

**Report by – Associate Professor Julie Bernhardt – 2012 Churchill Fellow**

**The Sir William Kilpatrick Churchill Fellowship to study environmental enrichment as a new treatment for brain injured individuals – Spain, Sweden, Finland and USA.**

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Signed:

Dated:



Julie Bernhardt

9<sup>th</sup> July 2013

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## Acknowledgements

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- Professor Thomas Lindon, Sahlgrenska University Hospital, Sweden
- Professor Lena Von Koch, Karolinska Institute, Sweden
- Dr Marie Elf, Högskolan Dalarna University; Chalmers University of Technology, Sweden
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- Dr Sandra Billinger, The University of Kansas, USA

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## Executive Summary

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### Project Description:

To travel to Spain, Sweden, Finland and the USA to study how enriching the hospital environment might contribute to improved brain function and recovery after stroke.

### I wanted to learn:

- In centres where enriched programs were established – what were the barriers and facilitators to adopting the program, and what standards or key performance indicators had been established to evaluate the program
- What is evidenced based architecture? And how might the environment change clinical outcomes
- How does enriching the environment with music listening contribute to brain recovery

By broadening my network I hoped to find rehabilitation centres of excellence that were incorporating evidence based design and/or enrichment into their care model.

### Highlights:

Visiting a rehabilitation program for Swedish stroke survivors held in Spain guided by the concept of environmental enrichment. Learning about the science of evidence-based design in architecture and discussing the challenges of building health facilities that can meet the pragmatic needs of stakeholders *and* foster enrichment activities that are likely to improve health outcomes. Discussing how music listening for 1-2 hours a day after stroke can improve thinking ability and memory and the possible mechanisms for this effect. Meeting clinical researchers who are studying how we can change the approach to patient care to be more patient centred and the potential contribution of this approach to improving outcome and successful transition from hospitals back to home.

### Major lessons and conclusions:

To achieve substantive changes and enrich hospital environments will require a collaborative approach across the health, hospital, and architecture fields. While there is emerging evidence from some areas for the benefits of elements of enrichment, ie changes have resulted in demonstrable improvements in patient outcomes, building the business case for change is a major challenge. It is imperative that a research framework is embedded within future enrichment programs if this field is to gain momentum. Developing an Australian interdisciplinary collaborative group in the field of environmental enrichment would be a good first step and is one of my key objectives for the next 12 months.

## Program

Date and Location	Meetings
<p>7 – 12 April</p> <p>Marbella, Malaga, Spain</p>	<p><a href="#">NeuroOptima</a></p> <p>Malin Lindh, Physician responsible</p> <p>Anna Sjöholm, Physiotherapist</p> <p>Helen Davidson, Co-ordinator, participant liaison, physiotherapist</p> <p>Anita Persson, Physiotherapist</p> <p>Johanna Zetterlund, Physiotherapist</p> <p>Marika Schütz, Speech therapist</p> <p>Participants/family members</p>
<p>15 April,</p> <p>Gothenburg, Sweden</p>	<p><a href="#">Chalmers University</a></p> <p>Peter Frost, Adj Prof, Architect, Centre for Healthcare Architecture</p> <p>Marie Strid, PhD, Project Lead, Architect, Centre for Healthcare Architecture</p> <p>Roger Ulrich, Professor of Architecture at the Centre for Healthcare Architecture</p>
<p>16 April</p> <p>Gothenberg, Sweden</p>	<p><a href="#">Centre for Culture and Brain Health, Sahlgrenska University Hospital</a></p> <p>Thomas Linden, Assoc Prof, Neurology/Psychiatry Sahlgrenska University Hospital</p>
<p>18 &amp; 19 April</p> <p>Stockholm, Sweden</p>	<p><a href="#">Karolinska Institute, Department of Neurobiology, Care Sciences and Society</a></p> <p>Lena von Koch, Professor, Karolinska Institute</p> <p>Marie Elf, PhD, Centre for Clinical Research, School of Health and Social Studies, Högskolan Dalarna University; Chalmers University of Technology, Gothenburg, Sweden</p>
<p>22 – 23 April</p> <p>Helsinki, Finland</p>	<p><a href="#">Cognitive Brain Research Unit (CBRU), Institute of Behavioural Sciences, University of Helsinki &amp; Finnish Centre of Excellence in Interdisciplinary Music Research, University of Jyväskylä, Finland</a></p> <p>Teppo Särkämö, PhD, Research Fellow</p>

<p>25 – 26 April, College Station, Texas, USA</p>	<p><a href="#">Centre for Health Systems and Design (CHSD), A &amp; M University, Texas</a></p> <p>Mardelle Shepley, Skaggs-sprague Endowed Chair in Health Facilities Design, Director, Center for Health Systems &amp; Design</p> <p>Susan Rodeisk, Assoc Prof, Faculty Fellow, CHSD</p> <p>Kirk Hamilton, Professor, CHSD</p> <p>Naomi Sachs, PhD student, Architect, CHSD</p> <p>Lou Tassinary, Professor of Visualization, Associate Dean College of Architecture</p> <p>Xuemei Zhu, Assistant Professor, CHSD</p> <p>Sherry Bame, Professor, Landscape architect and urban planner</p>
<p>29 – 30 April Kansas City, USA</p>	<p><a href="#">Department of Physical Therapy and Rehabilitation Science, KU Medical Centre, The University of Kansas</a></p> <p>Sandra Billinger, PhD, Lead, Metabolic, Strength and Energy Lab</p>

## Introduction

Stroke is a common and disabling condition, with one new stroke occurring every 10 minutes in Australia. Stroke-related disability impacts individuals, their families and the community and improving rehabilitation care to reduce disability is an important goal and one that I have championed over many years. As a physiotherapist with extensive experience in the rehabilitation sector, my clinical research has focused on developing and testing new rehabilitation based interventions for people affected by stroke. I am particularly interested in the development of broadly applicable interventions that may potentially reduce the burden of stroke-related disability. These have focused to date on physical activity as a result of my early research work highlighting that patients with acute stroke are inactive and alone throughout the therapeutic day [1]. However, in recent years, colleagues and I have become interested in the concept of 'environmental enrichment' (which incorporates social, cognitive and physical activity in an enriched environment). Environmental enrichment is a well established concept in animal research. The four key elements of enrichment in animals is the provision of housing with opportunity for socialisation, physical, sensory and cognitive challenge. We have shown in a systematic review of animals with induced stroke, that enrichment markedly improves behavioural outcome after stroke [2]. Over the last few years, we have started to pilot studies in humans that incorporate personal and communal enrichment. We currently know little about what model of enrichment may improve recovery after stroke or how enrichment may enhance recovery, but the opportunity to study and develop this promising, potentially broadly applicable intervention is exciting. While stroke is my key field of interest, the approach, if effective, would not only apply to those with stroke but is likely to be more broadly applicable to other hospitalised patients.

The concept of 'healing environments' is also gaining momentum and there is considerable overlap between the ideas underpinning healing environments and environmental enrichment. The book *Healing Spaces* by Esther Sternberg [3], provides a broad overview of this emerging area. Growing links between the fields of neuroscience and architecture have led to exciting discoveries in this field and highlight the many disparate areas of research currently underway. One of the challenges of researching this field is the considerable breadth of the area. My Churchill Fellowship allowed me to spend dedicated time with a range of individuals interested in the concept of enrichment and the effect of the environment of health behaviours and outcomes. I have only just begun to scratch the surface.

The following section details my observations and experiences at each visit. At the conclusion of each section I provide a key point summary.

## NeuroOptima experience, Spain

### What is NeuroOptima?

NeuroOptima is a unique program that is founded on the principles that the brain remains plastic even years after stroke and that intensive training in an enriched environment can yield positive results that can be sustained beyond the life of the program. The program runs for 3 weeks ideally but participants can attend for just 2 should they wish.

The location of the program is in Marbella, Spain, at the site of the Centro Forestal Sueco (CSF) a Swedish Forestry rehabilitation service set up many years ago (1960's) to provide rehabilitation for injured forestry workers. NeuroOptima has been running for the past 10 years on a needs basis (not all year round) and will only run when a sufficient number of participants have enrolled in the program (6-12). The CSF facility is not new, but the gym and pool areas are suitable for neurological rehabilitation training. The surrounding gardens where morning breaks are held are large and attractive. The weather is much more moderate than Sweden and outdoor activity is an important part of the program.

Most participants attend with their primary carer and/or other family members who are integral to the training. The program aims to deliver 5 hours of therapy per day, 5.5 days a week, with Friday afternoon and Saturdays free. The staff include a physician (available in the first and last week), physiotherapists (ratio 1:3), a speech pathologist if needed by the participant group (present for 10 training days) and co-ordinator who attends for the first week, or longer, to help the participants settle into the program.

In the first week, approximately 2.5 hrs is allocated for stroke education lectures and a Q&A session with the team. Patients and families attend these meetings and they are highly interactive (see 'Questions' section below). Participants have coffee breaks and meals together, including a special social dinner each week that is also attended by staff. This helps build a feeling of 'group'. Carers are encouraged to share experiences in separate formal and informal sessions over the course of the program.

### **How is it funded?**

NeuroOptima is self funded by participants. The cost is 85,000 Swedish Kroner (SEK) (AUD\$ 13,750) for a participant and SEK 25,000 (AUD\$ 4,050) for partners. Some pro-rata options are available for participants to stay only 2 weeks or for local participants (English or Swedish speaking<sup>1</sup>) to attend for several hours a day. There was one participant in the current program taking this option. The cost includes food, lodgings and training over the 3 weeks but does not include transport to or from Sweden to the program which is covered separately.

There is some opportunity for part refund of the costs of the program through a range of local sources in Sweden, predominantly via the Försäkringskassan (Swedish Social Insurance Agency), however reimbursement is not always certain. NeuroOptima provide information to assist participants with the reimbursement process and can assist with challenging claims in cases where these have been rejected. In short, up front payment is essential and many, but not all, claims are approved.

### **Who is eligible and how are participants selected?**

Suitable participants are those motivated to undertake the program who have sufficient cognitive function to allow them to engage in the program. The process for selection is a 2 step process. Interested participants contact NeuroOptima in Sweden. After information has

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<sup>1</sup> Approximately 70,000 Scandinavians live in the Costa del Sol area, 30,000 are estimated to be Swedish and a Swedish school operated close to CSF

been exchanged, those wishing to proceed are interviewed by phone using a standard format to establish their medical history, rehabilitation history, current status and future goals. Extreme physical disability is not a barrier to attendance if other pre-requisites are in place. Once patients are selected, they have a second interview at 2 months prior to attendance to confirm their medical status has not changed, further contact may be indicated to support the participants and their carers leading up to the program. *Note:* The doctor, to the program, Dr Lindh, suggested that a visit to the GP prior to the program should be recommended as a medical check.

The mix of abilities of the participants is important for determining the number of therapists required to attend the program and in the group I observed, there was predominantly highly dependent participants (7/8) making it challenging to set up group training – there was some ‘down time’ while participants waited for a therapist and this was recognised as not ideal and reflected more the participants in this program compared with previous programs.

A number of participants had attended the program in previous years and were returning for more training.

### The program

The attitude to all training and experiences is “have a go, try something new, take a chance”. The Sunday before the program begins, assessments and planning with participants is completed to establish the participants’ goals. Assessment includes balance, strength testing, upper limb dexterity, walking speed and endurance as well as specific assessments related to patient goals. No formal exercise/fitness testing is conducted.

The program runs for three weeks. A long morning session (0900-1300) is broken with a 30 minute coffee break outdoors if possible. A 2 hours break includes lunch and a rest period, which is followed by another training session 1500-1700 hrs. There is a strong focus on fitness and strength training in the program. Group sessions on standard bikes, which include interval training for those that can participate, are conducted regularly. In this highly dependent group, much use was made of the large wall frame for support and participants practiced balance work (double and single leg), stepping, standing steppers (weight shift), stretching and standing up from a chair.

A pool session is conducted once a week with participants assisted to walk down steps to enter the pool (shoes are worn to protect the feet). Most family members also went into the pool to assist or just for fun. Most work was walking, with weighted leg weights and some resisted work with upper and lower limbs in a floating position. The participants are encouraged to think about getting in a pool for training at home.

A beach session is also conducted once a week at different times/days. Those who don’t wish to swim are still encouraged to attend and do walking training in the sunshine (and wind) with different social/environmental stimulation. In the first week, one participant, Sif, went in despite waves and cold water to lie in the water. This required the assistance of 2 therapists but was highly successful from the participants’ point of view (big smiles) and was the first time since her stroke 2 years before that she had been in the ocean.

**Monitoring progress:** Each morning participants complete a timed 12 m walk. This is used as a motivating tool for the participants, helping them to track their progress. These are recorded on the wall but not obvious (the gym is multi-use with other programs), rather the participants are encouraged to watch and support each other. On the last day of the program, assessments are repeated. The physician interviews the participants about their thoughts of the program and their progress. On the second last day, participants complete an anonymous questionnaire (not sighted by me) about their experience of the program. This contains about 50 questions including the environment (food, weather), training (group, type, variety), coordinators etc. This is used to inform future programs.

### What makes this program an *enriched* program?

The physical **environment is highly stimulating** and enjoyable for the participants and their families. One family member interviewed said “it is great to be away, you can focus 100% on the program and it is easy to get around”. This was in part related to the challenge of getting about at home in Sweden during winter when it is difficult to go out. Participants regularly walk on grass, up slopes and over very irregular surfaces that are challenging and in most cases very different to their home environment. There is a strong **social** element to the program both for the participants and for the families. By day 3 of the program I observed that participants were talking with each other, and so were family members. The team quickly develop a sense of ‘group’ and there was much laughter, particularly in the pool session. The **physical activity** levels of participants throughout the program are very high, particularly in comparison with their likely (and stated) levels of activity at home. In addition to the training, participants are encouraged to walk to and from meals, the gym etc as much as possible. **Cognitive** function was not formally addressed except in those undergoing speech training with the therapist, but many of the physical components of the program incorporate some cognitive challenge.

### What questions did participants have for the team?

Following the information formal session early in the program, an informal “Ask the team” session was conducted (in Swedish). The main questions were:

- How hard do we have to train here in order to keep the gains made at NeuroOptima?
- Is it OK to take a holiday?
- What can I expect in a few years time if I keep training hard? (Speech)
- What about vision, who can help with this?

The session was very interactive and participants and family members were engaged.

### What happens at the end of the program?

Transition back to the community and life after the program are key issues for the success and long term sustainability of this program. I asked the rehabilitation team how do the participants continue to train in the absence of this environment and without the support of the therapists?

The therapists hope that the (in most cases) large improvements in function and change in attitude (‘have a go’) will translate into better function at home. In the final week the program

which the therapists develop over the course of the 3 weeks is transferred into a written program for the participants to take home. This includes digital photographs of the participant undertaking the exercises, with text describing the exercise and giving tips specific to that individual.

At present there is no follow up of participants, however plans are afoot to provide a follow up phone service with possible face to face support as required (at cost).

#### Summary of key points & reflections:

- There is evidence that rehabilitation in the 'chronic' phase after stroke is effective in improving outcome[4]. Despite this, access to late stage rehabilitation is scarce in Australia and elsewhere. The success of the NeuroOptima program over many years is evidence of a demand for these types of services
- The location of the program (off site, resort style) contributes to the 'enriched' nature of the program. How critical this is to its success is uncertain
- For programs to be attractive and worthwhile, there needs to be evidence that the improvements seen during the program are sustainable beyond the program

# Centre for Health Architecture, Chalmers University of Technology, Sweden

## Why visit here?

The built environment can strongly influence the sensory, social and physical activity of the staff and patients in that environment and consequently impacts on health. The Centre for Health Architecture, Gothenburg, is a relatively new initiative (3 years) of Chalmers University of Technology, one of the largest and most eminent technology universities in Europe. Here I met with lead researchers, Marie Stiv, Peter Frost, Roger Ulrich and others to discuss what makes Swedish health architecture innovative and to better understand the planning processes in place to facilitate good interactions between health care providers and architects. The group have worked on approximately 30 health care projects to date.

## Achieving good health care design

Peter Frost and PhD student Johanna Eriksson outlined their approach to developing a 'design dialogue' between architects and health care providers that they believe is evidence based and helps to get the best outcome for the building based on: first, what the goals are for the patients and second, how the staff need to work to meet these goals. This approach normally unfolds over a period of weeks through use of workshops and tools to help health care providers to articulate their needs. A highly skilled facilitator is key as are getting the right people around the table (users, not just managers). They have yet to identify a good way to interact with patients themselves but consider that a consultation process with patients/families outside of the design dialogue workshops could be helpful. The general view that the old approach of replicating "standard" buildings is not the way of the future, but that a mix of 'taking the best of what we know' in combination with design dialogue approach (so called integrated planning) could be the ideal option. In discussing the reality of working to a budget, Roger Ulrich commented that with some design elements it may be possible to 'make a case' for increased expenditure if the cost of not doing something would lead to worse patient outcomes that would increase costs in the long term. This is particularly true for prevention of spread of infection (eg single bed rooms) and will be discussed further later in this report (see Centre for Health Architecture, Texas A&M, page 20).

Discussion of elements of the built environment that can influence patient outcomes included: therapeutic gardens, with some examples provided by Roger Ulrich of garden design research, colours, sound (techniques to reduce sound within a hospital), single patient rooms to reduce infection, decentralised nursing stations with line of site to rooms to reduce falls in patients at risk.[5] A recent re-development of a mental health facility in Gothenburg has seen the rates of aggression reduce dramatically compared with the previous facility with the same staff.<sup>2</sup> The evaluation for this project used a pre-post design with measurement of important health behaviours in the two environments (before build and

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<sup>2</sup> <http://www.chalmers.se/en/news/Pages/Good-architecture-brings-lower-levels-of-violence-in-psychiatric-care.aspx> (for story)

after build). This approach helps build an evidence base for the effects of architecture on health. The publication reporting the results is in progress.

### Helpful comments on my proposal to enrich the environment

I presented a summary of my research to date to provide the context for my interest in environmental enrichment. This included my behavioural mapping work conducted over many years in a number of stroke units both in Australia and Internationally,[1, 6] the AVERT trial of earlier and more frequent rehabilitation with a focus on mobility which is in the final stages and includes over 2000 stroke patients,[7] and our preliminary work on introducing an enriched environment protocol (with personal and communal enrichment activities).[8] To date our focus of research has largely ignored the physical (built) environment. We discussed how the built environment might be created to enhance social, cognitive and physical activities and to improve health. Significant discussion was had around the trend for single patient rooms (which can increase patient isolation, particularly in people with communication disorders) and the kinds of ‘carrots’ that you could introduce to draw patients out of their rooms. Also how to reduce the ‘passive patient’ effect of health care environments. I raised the issue of how the environment ‘affords’ certain behaviours, and the potential for environmental affordances to drive behaviour in a positive way. Roger indicated that very little work had been done in this area but that it would be an interesting challenge to work on a strategy to increase activity in hospitals. Roger also indicated that if my large AVERT trial is positive, then working with an experienced healthcare architect to model how you might create the right environment for this kind of program would be extremely valuable. Roger expressed his strong view that to date we have done a “terrible job” in health care internationally with hospital design, developing hospitals that ‘discourage and punish’ patient autonomy and physical activity. His view is that if you had the data to provide compelling evidence of the benefits of greater activity (for example), you could get the push needed to design a building that promotes activity. “We design to encourage passivity” says Roger and I agree. This could be changed and is one of my goals for the future.

We also discussed the benefits of tracking patient movement throughout a space and I described our unsuccessful efforts to find technology that could readily be applied in a hospital setting. Roger suggested that equipment tracking technology may be modifiable for patient tracking. I have made some contacts since the visit and will continue to pursue this area.

#### Summary of key points & reflections:

- Evidence-based health architecture is a relatively new field that is likely to influence design into the future. Research methodologies are still being established
- Strong links between clinicians, architects and researchers would help advance this field
- There is significant scope for the findings of current clinical studies, particularly relating to patient activity and autonomy, to help drive dialogue and change if partnerships are in place
- Rehabilitation has not been a focus in health architecture reform to date

## Culture and Brain Health initiative, Gothenburg University, Sweden

[From the website<sup>3</sup>] “The brain and nervous system of a human being are constantly influenced by various types of sensory stimulation from the environment in which we find ourselves. An enriched environment is necessary in order for us to be able to keep our brains intellectually intact when we age and it is also a cornerstone in modern rehabilitation programmes for people with brain damage. In the objectives of the research programme **The Culture and Brain Health Initiative** there is a component of increasing the understanding of the brain's plasticity and healing capacity. Investigating the effects of sensory stimulation through various cultural activities, such as music and dance. One of the purposes is to understand and exploit culture's possibilities to achieve improved prerequisites for brain health, good ageing with a maintained cognitive function, as well as increasing the chances of healing and regaining functionality after damage and disease in the brain. The research programme is interdisciplinary and comprises cooperation between neuroscientists, musicians and musicologists among others.”

### ‘Culture’<sup>4</sup> an emerging focus in health care research

The Culture and Brain Health initiative was an innovative and ambitious project that is coming to an end. I was interested to understand from a research perspective the outcomes (and challenges) of taking this highly interdisciplinary approach. I asked Thomas Linden, a participating scientist and clinician, to describe how the initiative was developed and what he saw as the main achievements of the initiative.

Thomas sent out a question to his broad network about whether they would be interested in participating in a research school around health and culture and he was inundated by responses, particularly from art disciplines, philosophy, political science and religion. Many existing projects were underway outside of the academic world. Thomas expressed surprise about the extent of research from different sectors and his excitement about how these could intersect with health care in the future. He also saw the importance of developing a research framework to advance the field.

To Thomas ‘culture’ is a refined means of enriching the environment and comes from a desire to find enrichment paradigms that unlock the same findings we see in animal experiments. Art is a key focus of the built environment in Sweden, this is regulated and a certain budget must be spent on art in health care environments. “Lighting, placement of furniture, decoration, gardening, green activities, there needs to be a greater focus on that, not just put professional people in place” if we want to enrich.

I asked Thomas how do you define success in the area of culture? “It can be tricky to get an agreed framework, art science is different to medical science.” That was a key challenge of the new research centre.

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<sup>3</sup> <http://www.ckh.gu.se/english/research/culture-and-brain-health-initiative/>

<sup>4</sup> “Culture is the garden you are laying out, the film I am watching, the choir in which we are singing. But culture does not only mean experiences and activities that someone is carrying out on their own or is sharing with others. Culture is also habits, apprehensions of morality, values, in short, the “sphere of life” and the meanings we share with others as members of a social community and that express what is meaningful.”

He described two key achievements: 1) developing studies (including a trial of 'medical dancing' and horse riding) and 2) raising awareness of the use of cultural activities as sensory stimulation and environmental enrichment in rehabilitation and other settings.

### **Cultural activities that combine sensory stimulation, physical activity and social interaction are potential 'interventions' for rehabilitation**

An example of this is 'medical dancing'. Dancing involves sensory stimulation (eg touch, vision), cognitive function (eg coordination, attention), physical activity and socialisation. It has been shown to be feasible, enjoyable and to have health benefits in older people [9] and to slow progression in Parkinsons disease [10]. But to run studies like this effectively you need input from both medical and artistic areas. The current study initiated within the Culture and Brain Health project, which compares rhythm therapy with horse back riding, is ongoing.

### **Lessons learnt**

The complexity of studies exploring culture and brain health is high. As you bring in more disciplines, and try to accommodate many perspectives, it takes longer to design the studies (with input from all disciplines) and a long time to finish them. On reflection, Thomas felt that perhaps they started too big, and it may be better to start with smaller, more focused studies that are easier to finish then build on this with follow up studies.

I asked his views on how many people should sit around the table. Thomas felt that if you want to brain storm, you can have more. If you want to nail down a problem it should be smaller. Their group was very large at times, and included some external advisors who were brought in on occasion. Thomas suggested that seminars for discussion might be a good approach with a smaller core team of people to devise and design studies in the area. Balancing inclusion with efficiency can be challenging. Mechanisms for connecting with people at different times who may not be in the core group may be important to sort out.

#### **Summary of key points & reflections:**

- 'Culture' is an emerging focus in brain research with limited studies in brain injured populations to date. Starting the conversation is the first step
- Building a framework for research that bridges medicine and arts can be a challenge and needs careful thought but is worthwhile

## **Karolinska Institutet, Department of Neurobiology, Care Sciences and Society, Stockholm**

### **Patient-centred care – could it reduce the “passive patient” phenomena?**

Patient-centered care focuses on the patient and that individual's particular health care needs. The goal of patient-centered health care is to empower patients to be active participants in their care. [11] This approach marks a significant shift away from the traditional models that focus on the doctor or health professionals perspective, towards an approach that places the patient or client at the centre of decision-making, goal setting and organisation of services for their care and adopts the patients' perspective. [12]

In neurological rehabilitation, it is often believed that the care model is patient-centred, however Lena's research team have studied this over many years and have found that many teams talk of patient-centred care but in reality their care practices are very traditional. Traditional practices include inflexible schedules (eg only being able to shower at a certain time of day, limited visitor hours, no opportunity for autonomous movement around the facility), insufficient sharing of information to allow patients to be informed enough to participate in decision-making, narrow goal setting opportunities (eg in line with therapist goals but not beyond), and not offering hope or preparing patients for life after discharge. [12] My discussion with Lena and Marie focused on two key areas: can the environment influence patient-centred care and how might we shift existing models when they are identified as being health professional centred to a more patient-centred approach.

### **Can improving hospital design improve patient-centred care?**

Marie Elf, a nurse with a PhD in architecture, is focused on using system dynamics to help build new facilities that aim to enhance safety, patient-centred care and high quality care. While quality indicators and 'evidence based design' in Sweden is very prominent, there is no standardised system of measuring design quality. She has built a model of the health system that shows the complex interactions in health care and the goal of the service (including quality of care) to act as a framework for designing new buildings or renovations of buildings. She has also validated this system and established methods of measuring the quality of the design that is established. This has not been done well before – ie, measuring whether the needs of the staff and patients have been met at the end of the design process. Marie's experience is that participants in redesign (staff) come to the meetings expecting to discuss room, instead with her model, they are asked to consider patient care and use system analysis to design a new system. Lena von Koch has been conducting independent interviews to establish the participants' views about this new approach. They have now used this approach with intensive care, thoracic surgery and aged care redesigns to name a few. The results of the qualitative interviews are pending. Marie is very clear that a current major gap there is no evaluation of the design outcomes (were the goals met) at the end of a project (post occupancy). The main reason for this is that there is no clear line of responsibility – who's job is it to do this? Marie is now doing pre-post evaluation for a number of projects using structured observation.

I reflected during this discussion that my own and other behavioural mapping studies have consistently shown that 'therapy areas', dedicated spaces for physiotherapy and

occupational therapy are very under utilized in stroke care [13]. This has led in part to my belief that it is time to revisit the traditional idea of a dedicated therapy area away from the ward. Lena indicated there is some evidence that therapy areas are where patients are least likely to be autonomous and much less likely to be involved in decision-making about their care [14, 15].

### Changing thinking, becoming a patient-centred care practitioner.

Lena and colleagues in her group presented a range of research projects that are founded on the idea of changing practitioner (usually therapist) behaviour to become more patient-centred. The comment was made several times that therapist's get offended when they are told that their current care approach is not patient-centred. This highlighted the challenge of getting staff on board to try a new approach to developing care goals and practices *with* the patient instead of *for* the patient. A number of clinical trials currently underway are testing a model to move clinicians to a more patient-centred approach, with qualitative work conducted in parallel to explore the themes of patient-centred care. Senior researchers Susanne Guidetti described a 9 step person centred training approach which has been trialled by the group and following which some units expressed a significant cultural shift in care approach [16]. We discussed whether this model was ready to roll out but the group felt that it needed to be evidence based and that current evidence was still lacking. I asked how long it might take to change thinking and practice based on their experience. Lena indicated that their work suggests this depends on both the context of where the therapist works (system constraints and pressures) and individual willingness to change. This means, not surprisingly, that a range of factors are at play and that implementation approaches need to be flexible.

I asked their views about whether current models being developed and tested may apply to the whole team providing care. Where teams already work transprofessionally, which is usual for rehabilitation care, this is probably feasible, and in fact the group felt that training together as a team would be highly desirable.

Prof Eric Coleman, Colorado University ([www.caretransitions.com](http://www.caretransitions.com)), was an invited speaker to the group and gave a great lecture titled "Infusing person-centred care to improve quality and safety during handovers". He spoke of the significant push in the USA today to monitor quality of care and to penalise hospitals for 'excessive re-admissions' that indicate transition from hospital initially was probably not well done. Considerable investment has been made in the USA to improve health literacy of patients, linkage with community agencies and competence of patients to manage their condition when they leave hospital without significant help from health care providers. Eric has established that the 3 key reasons for readmission are: 1) poor health literacy, 2) reduced cognitive function and 3) poor 'locus of control' ie health care providers take charge instead of getting patients to take charge. He has designed an intervention founded on the idea of the 'health professional as coach' for a short period of time (1 month with small amounts of contact). This has led to reduced re-admissions @30 days and also at 90 and 120 days (beyond the life of the coach/patient interaction). The intervention is argued to be cost neutral or cost saving, although formal health economic evaluation of the program does not appear to have been undertaken.

After discharge from rehabilitation, patients often feel 'abandoned'. [12, 17] The interesting idea that comes from Eric Coleman's work is that developing health care systems that foster health care competence in patients may not only improve their ability to engage in their recovery better but may also help them to stay out of hospital once they return home.

#### Summary of key points & reflections:

- The built environment influences patient, family and clinician behaviour and good design is likely to improve the quality of care we provide. However, staff attitudes and behaviour, including the practice of patient-centred care are also considered key to good quality care (from the patient/family perspective) and an enriched environment.
- Equipping patients and families with the knowledge and skills (while they are in hospital) they need to manage their own health when they get home is currently poorly done and likely to be the focus of quality initiatives in Australia as it is in the USA. For people with brain injury and long term disability, this should be a key area for action.

## Cognitive Brain Research Institute, University of Helsinki

### Music listening improves brain recovery after stroke

Here I met with Teppo Särkämö about the potential for auditory enrichment to be incorporated into rehabilitation for people with stroke and his research which aims to better understand the effect of music on the brain. Teppo described how emotion and music are closely intertwined, and music also triggers memory. In general, Teppo feels that music may serve as a stabilising function, particularly in the first few months of stroke. It may allow patients to trigger memories and emotions that may help them in the early period after stroke. However, he has also shown that music listening can specifically change thinking function when applied for 1-2 hours a day in the first 3 months after stroke. In his study of 60 patients with middle cerebral artery stroke, those patients randomised to daily music listening, compared to those randomised to speech listening with audio books, or controls, showed improved verbal memory and focused attention.[18] Measurement occurred early (1 month) and late (6 months) and verbal memory and attention were key outcomes in this first trial of music listening. Visuospatial tests and visual tests showed no change over time. Interestingly, 63% of patients in this trial when tested using the Montreal Battery Evaluation of Amusia (MBEA, 45 mins to administer) were shown to have 'amusia' – a deficit in perceiving music [19], a rate much higher than in the healthy population, suggesting that stroke may result in amusia (although the cognitive challenge of this test is considerable and the mechanism is not clearly understood). While amusia did not change over time in these patients, cognitive function did. Teppo used EEG magnetoencephalographic (MEG) testing to examine auditory sensory memory and the MMN response. The changes observed in MMN supported a strong association between music listening and cognitive recovery. The neural (brain) basis for this recovery is unclear, however, Teppo and colleagues believe that one potential explanation is that exposure to auditory stimuli enhance plasticity in the recovering brain. Music listening activates a large brain network that includes prefrontal,

premotor, temporal and parietal areas of the brain. It may therefore stimulate peri-infarct and contralesional areas of the brain that are notably susceptible to changes early after stroke in patients with middle cerebral artery infarcts [18]. Enriched sound environments in rodents have also enhanced glutamate expression in the brain, which is another potential explanation for enhanced memory and attention found in his study.

### **What are the pragmatics of setting up music listening in people with stroke?**

I was interested in the rates of refusal for participation in a study that required patients to listen to music as part of a trial. Teppo told me that refusal rates were very low, with very few patients hating music, and the most likely reason for refusal being that they were emotionally labile (rapid mood changes, often with crying), which is not an uncommon consequence of stroke, and can be distressing for patients. In choosing music for the study, Teppo took the view that individual preferences are very important. In his study, a music therapist interviewed the patient and/or family to determine the preferred range of music for that patient. They then compiled a selection of 10 CD's for the patient and provided them with headphones (preferably noise cancelling) and audio play devices in the first instance. Music cannot be genre specific and may need to range across genres depending on their mood and this would be reviewed weekly (with family support) to modify or add to the selection. Simple systems and training are needed so patients can use the devices without too much assistance. I asked if they tracked how long patients listened to music, this is not necessarily simple but technology may help with this. Teppo used a recording sheet for this in his trial. Some patients listened for 4-6 hours per day, these tended to be people with lower mobility or who remained in hospital longer than other patients. Patients with aphasia were included in the trial, Teppo commented that those randomised into the audio books group who had aphasia would find long books difficult to listen to, and may prefer short stories or even jokes instead of full length books.

Teppo and I discussed the poor auditory environment that is typical of hospitals. The hard surfaces can lead to noisy environments where the high decibels invoke stress, not rest and healing.[3] It is possible, that music listening may help healing by reducing stressful noises within hospital, however the superiority of music over audio books in Teppo's study suggests that music in and of itself induces brain changes that are sustained over time. When the built environments do not allow for personal space (eg multi-bed rooms), it is possible that music can allow for a person to create their own personal space.

### **The next steps for understanding the effect of music on the brain**

Teppo has commenced a new study that will extend his work, and will include emotional prosody (for example words said with a happy, sad voice) as another outcome to test the hypothesis that amusia is linked to deficits in emotional prosody, and whether music listening, which has a strong emotional effect, may alter over time. Teppo will include fMRI protocols with instrumental and lyrical music and poetry as stimuli which will be used to explore the effect of these different cues on the brain. This is an exciting area for brain research. We also discussed the work by other groups, including Prof Schlaug, who are exploring the use of singing to help patients with aphasia (language disturbance) learn to speak more fluently,[20] another potentially fruitful area for research and future application in stroke recovery.

### Summary of key points & reflections:

- A music listening protocol can be implemented with people with middle cerebral artery stroke, and if preference-based, is voluntarily used for at least 1 hour a day and resulted in sustained changes in memory and attention
- Understanding of the mechanism by which music results in brain changes is in its infancy

## Center for Health Systems and Design, Texas A&M University

### Evidence based health design

The centre is one of the largest and active research departments focused on health architecture in the USA. There are 39 Fellows in the department and 2000 students. Although most of the fellows are architects, the group have strong interdisciplinary links with a range of other academics. Here I met with the Director of the Centre, Mardelle Shepley and her team who are leading academics in this area [21, 22] and was invited to presentations from undergraduate, Masters and PhD students in the fields of health care design. The projects students were working on ranged from elder care facilities (Design studio of Susan Rodeisk) mixing high level “skilled nursing” care with more independent “hostel” style accommodation, children’s hospitals for the deaf, and research into healing gardens (Naomi Sachs). Fellows are focused on a range of strategic areas including landscape design, building better health facilities and building better communities that promote health. The group have strong links with China and consult on projects in Qatar.

### The Fable Hospital, an evidence based design template for the future

I interviewed Dr Kirk Hamilton, architect and senior researcher [22, 23] in the centre. Kirk is one of the co-developers of the Fable Hospital [24], a virtual hospital that combines the best of evidence-based hospital design. Kirk acknowledged that only about 5% of the design is truly underpinned by evidence but that the design is also based on common sense and best principals. The Fable hospital has recently been updated (Version 2.0[24]) and this model was used when building a new hospital in Ohio (Ohio Health Dublin Methodist Hospital [www.ohiohealth.com/dublinvirtualtour/](http://www.ohiohealth.com/dublinvirtualtour/)).

The challenge for continuing to develop the evidence base for good design is considerable. Following my discussions with Kirk and a range of students, these challenges include: 1) funding for health architecture research is difficult to obtain, the science is considered too ‘soft’ and there are few places where this area is a good fit with existing funding streams; 2) it is currently difficult for architects to gain access to the facilities or patient/staff populations to conduct research, with ‘patient privacy’ often noted as the reason to decline access; 3) there are too few researchers in this emerging field and 4) there is inherently a tension between clinicians and architects around \$\$ investment in hospitals. This means that if there is discussion over whether money should be spent on the building features to improve health, or on the health professionals within those building to improve health, clinicians want to fund people over architecture. Building a case for evidence based design is complex, particularly in a field where the evidence base is not yet very strong.

I reflected here that in the 11 years of my involvement with grant reviewing and panels for the NHRMC (National Health and Medical Research Council) I have never reviewed a grant

that aims to test the effect of the built environment on health outcomes, or includes architectural considerations as part of the research question.

### Rehabilitation examples of excellence?

The group could not direct me to any examples of rehabilitation design that stood out, particularly as they relate to increasing physical, social and cognitive activity that forms the triad for enrichment. While there are a number of examples of well rated hospitals that provide rehabilitation, in their opinion, the designs of these buildings are not innovative. I took the opportunity to visit a local rehabilitation facility at St John's Hospital. This is a well regarded facility in College Station. Our tour guide was an experienced nurse, Sarah, who has worked on the unit for many years.

The design of the building was a standard, low level design with good views of the outdoors from all patient rooms. These were mixed single and double rooms with one room called the ADL apartment which incorporated a lounge area with low couches, kitchen and a bedroom that can accommodate a double bed. This was generally used for patient/carer training pre-discharge (although Sarah noted that the room was under utilised and probably should be used more often). The nursing staff practiced continuity nursing (caring for the same patients throughout their stay on consecutive days) and patients ate all their meals in a light filled communal dining area. Standard therapy of 3 hours a day applied although the nurses had no clear idea of what that entailed and lamented that "the patients don't do the same things for us as they do with the therapists". This is a common issue in rehabilitation. Nurses did not go to the therapy room which was located remote to the patient areas. Separation of therapy and patient areas is a common barrier to high quality, patient-centred care and is in part related to the environment design as well as the policies and practices of the unit. Family were allowed into visit patients at any time but with the exception of the ADL apartment, they could not stay with the patient. The surfaces in the building were hard, probably noisy during the day and the lighting in the main part of the building florescent. Length of stay was between 7 and 14 days with those who required further care (and could not go home) discharged to a skilled nursing facility (nursing home). Patients did not manage their own medications close to discharge and were educated about their meds in a single session with the physicians on the day of discharge. This is standard practice and part of the problem with existing care models noted by Dr Eric Coleman (see page 17).

#### Summary of key points & reflections:

- The Fable Hospital provides an evidence based template for hospital development, it has now been built in Ohio with further hospitals planned. There is no rehabilitation component to the Fable Hospital.
- Better links between clinicians, researchers and architects could advance the evidence base for this field

## **Department of Physical Therapy and Rehabilitation Science, KU Medical Centre, The University of Kansas**

### **Patients are sedentary in single bed rooms**

Sandy Billinger is an exercise physiologist and physical therapist with an interest in promoting physical activity in people after stroke. She runs an exercise laboratory at the hospital and conducts activity research with stroke patients. She has monitored physical activity using accelerometers in acutely hospitalised patients within a single bed room environment and shown that patients are extremely sedentary (inactive) for most of the day. Sandy attributes the environment as a significant contributor to the sedentary behaviour they have seen in their patients. To quote Sandy, "They are not moving, they are lying in bed or sedentary, everything is right there for them, the call button, the TV, food is brought to them, we are doing nothing to promote activity". In the US there is an emphasis on reducing risk, so falling is a major consideration and significant re-education would be required to make staff comfortable with patient activity. Even in those patients with the capacity to move and move well, "they too are in bed, they don't move". Doors to rooms are also most often closed to allow patients privacy, "cutting them off from things going on in the unit". Sandy believes that family engagement is important and hospitals need to be designed to promote activity. I agree with this view. Sandy reflected that in heart attack, a radical change occurred in the 60's when someone decided that the heart was a muscle and so could be exercised. This resulted in a major shift in care over the next 20 years to one of very early exercise after acute myocardial infarct (heart attack). Stroke continues to lag behind.

### **How fast do people with stroke lose fitness after stroke?**

I asked Sandy how quickly she feels people lose cardiovascular fitness (because the evidence base for this early time point is quite small). She feels that within 3 days there is a significant CV fitness loss, but it is difficult to tease out whether it is the stroke itself which causes early fatigue and shortness of breath or something else. She described a lady who regularly walked 3 miles a day and within a few days of stroke could only complete 3 minutes of a 6 minute walk test, despite having a relatively small cerebellar stroke. In reality we don't yet know how fast CV fitness changes after stroke or why. This requires further research. I asked Sandy what level of pre-exercise monitoring would be needed to 'clear' patients for exercise in their rooms if you were to provide exercise equipment (eg bike) to a patients' room. Sandy's view that for most patient, who have continuous monitoring on 24/7 in the acute period, that it would be minimal.

### **Visit to the stroke unit**

We visited the unit to review the environment. The ward has single bed rooms around the periphery with window access. The corridor is wide with a 'walking track' outlined in the linoleum (rarely used) but otherwise no incentive to use the walking track or use the back-to-back seating for rest. There are no areas for socialising or for activity in an attractive environment. The therapy room is a 2mX4m room with no windows that was used as a store room at the time of my visit. Sandy did not view this design as being stimulating or supportive of activity outside of the patients' room.

### Summary of key points & reflections:

- In this US hospital with 'gold standard' single bed rooms, physical activity of patients is extremely low and there is considerable room for improvement in activity levels
- Cardiovascular fitness changes quickly after stroke but we don't know the relative contribution of stroke and/or bed rest to this loss. More research is needed

## Conclusions and Recommendations

Environmental enrichment is a relatively simple term for a complex set of activities (physical, social, cognitive) that by its nature will be influenced by the physical environment and the policies and attitudes of staff. This made it somewhat challenging to research the field and I elected to split my time between centres of excellence in health care design as well as visiting scientists and clinicians studying a number of different enrichment activities (notably music and physical activity). Unfortunately, on this research trip, although I was seeking to visit or become aware of rehabilitation centres that were considered to exemplify evidence-based design and be cutting edge in their policies and processes, the groups I visited were not able to direct me to any. This is not to say of course that none exist, rather that I have simply scratched the surface on this occasion and that further research is required.

However, it may also indicate, as Roger Ulrich suggests, that there is an opportunity to develop an innovative model of health care for rehabilitation that significantly improves patient engagement and activity. That is an exciting possibility.

Throughout the report I have provided key points and reflections related to each of the visits I made during the fellowship. In formulating my final recommendations I have focussed on what I, as a health researcher and clinician with a broad network, could do to help drive the development of enrichment in Australia and also on what in general I believe would help to further develop the field.

### Recommendations

- **Broadly promote and hold an 'environmental enrichment' forum for interested parties to come together to discuss the issues, share views and form partnerships.** I will facilitate the Forum which will be open to all interested parties and will provide a platform for bringing interested individuals and groups together. There are pockets of activity in this area throughout Australia, but finding interested individuals has been challenging. The forum will provide a point of focus and while it may not yield immediate results, over time it is likely to lead to co-operative ventures and advances in research and practice.
- **Contact local and international health architects and researchers to foster better linkages between clinicians and those who design hospitals.** An early obvious step is to work with architects to establish an agreed framework for evaluating in a standardised way the physical environment of hospitals in which we conduct our clinical research. Better linkages should improve access architecture

students have to clinical sites to help build the evidence base supporting the influence of design on patient outcomes.

- **Work with architects and IT innovators to develop the “Fable Rehabilitation Unit” to complement the current Fable Hospital and promote the design of standard hospital wards that promote physical activity for better health.**

Designing the “Fable rehabilitation unit” would provide a template for new hospital design or redesign when the opportunity arises. This unit should also incorporate cutting edge IT to support patient care, information provision and research.

- **Conduct the planned Phase II and III trials of environmental enrichment.** We are currently working towards the conduct of a multi-site Phase II trial of environmental enrichment that will incorporate learnings from this Churchill visit. An application to funding bodies has already been submitted for the first multi-site (pilot) trial and, if successful, further application for the large Phase III trial will be made in the future.
- **Work with interested parties to establish a model of environmental enrichment for rehabilitation after brain injury that incorporates not just the physical environment, but also the changes in policy and practice required to enable patient-centred care in an environment that promotes faster and better recovery after brain injury, with successful transition home.** This will require a consortia of people from across policy, administration and practice areas willing to undertake transformational change. Research should be embedded as part of the change process and outcomes carefully evaluated.

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