

Wallace

**PROVIDING THE BEST
SUPPORT FOR CLIENTS
THAT NEED
HOSPITALISATION**

10TH ASSID DISABILITY SUPPORT WORKER CONFERENCE,
Melbourne, November 2010

**How can a Disability Support
Worker provide the best support
for their client who needs
hospitalisation?**

Associate Professor Robyn A Wallace
Director SHAID* Clinic,
Calvary Health Care Tasmania, Hobart

** Specialist Healthcare for Adults with Intellectual Disability*

Example

- 34 year old single woman with cerebral palsy and moderate intellectual disability
- Lives in group home with 24 hour care
- High physical and practical needs, epilepsy, PEG nutrition, multiple medications, spasticity, reflux, osteoporosis, mobile on chair
- Communicates using vocalisation and some adapted makaton; continent with signing
- One weekend her PEG tube falls out

..... continued

- Relief staff member calls ambulance
- Taken to hospital “the tube fell out”
- No person and no documentation to accompany her
- Left in ED for 10 hours in side room
- Became agitated, incontinent, no nutrition or usual medications given- nuisance to staff; junior doctor sent to attend
- Sent home with the wrong tube *urinary catheter*; no PEG
- Had seizure at home, readmitted and nasogastric tube inserted, urinary catheter removed
- And readmitted a week later for PEG reinsertion under general anaesthesia

What's wrong here?

What's bad with the care?

Who's fault is it?

How can it be prevented?

What's our role?

....it takes four to tango

- Let down by Herself
- Let down by Support Worker
- Let down by Service Provider
- Let down by Health Professionals

Patient suffered serious health side effects from poor care

Poor communication, inefficient, expensive, preventable

Support Workers have a major responsibility
in the *healthcare* of their
clients with intellectual disability

....I believe Support Workers could accept
the role of *leadership* in this area of care

And.....

- ...so does the patient have responsibilities
- ...so do the health professionals have responsibilities

Leadership by Support Workers

Leadership by Support Workers

- Facilitating Patient involvement and responsibility in their own care
- Defining and preparing Support Worker role for each person who requires hospital care
- Learning more about health issues in practical terms
- Assisting Health Professionals- first about the patient and their care; later about disability issues

***Support Workers helping their
clients with intellectual
disability in health matters***

**Support Workers help health in their
clients with intellectual disability**

- Research themes for patient with intellectual disability needing hospital:
 - Fear and anxiety
 - Practicalities of being in or attending hospitals
 - Discrimination and negative comments
 - Behaviour problems

Quotes from papers

Addressing fears and anxiety

- Hospital procedures, location, what happens, photos, driving by, visiting first
- Understanding what is happening appropriate to level of intellectual disability
- Behaviour rules, waiting
- Strategies to helping cope with waiting
- Company of organised, unflustered, well known Support Worker
- Setting the example in communication
- Care and compassion
- Know where loos, cuppa, parking, access

Addressing discrimination and negative comments

- Works both ways and often two sided
- Help the health professionals by being professional yourself
- Set the example in how you interact with client
- Show patient as a person
- Aim to have same treatment for same condition
- Know how to make a complaint about service provider and health provider

Communication

- With health professionals
- With patient about their health
- With rest of team at home
- With Person Responsible
- Support Worker to inform the Health Professional of the understanding of their client; acknowledge accurate level of intellectual disability
- Knowledge of why there, who seeing, be prepared

Behaviour problems

- Anticipate beforehand and work out if need additional Support Worker for that reason
- New or usual-working out cause may require some teamwork
- Address fears and anxiety
- Support Worker has major role and responsibility in managing behaviour

***Support Workers learning
more about health of people
with intellectual disability***

Aspects of health

- ***Healthy living at home***- diet, exercise, weight, immunisations, smoking, dental, bp, cholesterol, breast exams, Pap smears, prostate, hearing and vision
- ***GP***-primary care and main doctor
- ***Hospital***-more serious illnesses; emergency, outpatients and inpatients; high chance of needing hospital level care; few have private insurance; referrals needed
- Assisting ***client*** to take responsibility of their health in the way they can

Yes, the Support Worker does have to know about some health

- Multiple medical problems per person
- High chance of need for specialist inpatient or outpatient attendance
- Need to know about some of the common medical problems: epilepsy, bowel problems, nutritional problems, many medications, syndromes, musculoskeletal and other problems like strokes, heart attacks, arthritis, surgery
- Need to know the medico-legal concerns

Types of health problems requiring hospital contact

- Epilepsy-status epilepticus, seizure control, medications
- Syndrome related conditions
- Gastrointestinal-PEG, nutrition, pain, gastro
- Musculoskeletal-falls, fractures, spasticity, equipment
- Medications review, mix up
- Acute illness such as pneumonia other infections
- Accidents, any Emergency
- Tests- radiology, cardiology, dental
- Plus heart attacks, shortness of breath, stroke, chronic illness, arthritis, infections, gall bladder, operations, cancer

In service and training for health matters education

- Support Worker to agitate, Service Provider to fund education and discussion
- Homework as well; internet resources
- Conferences
- Incorporate health talk into weekly house meetings
- Syndromes, consent and medico legal
- Not expected to be a Health Professional but well informed lay person

Knowledge about medico legal

- Consent
 - Paid carers cannot give consent
 - Paid carers can advocate
 - Person Responsible, Statutory Health Attorney contacts have on hand before appointment
 - Notify PR or SHA of appointment
- Appointments
 - Paid carers cannot cancel specialist appointments if referral made by GP

Knowledge about what the Health Professional wants

- Accurate story of what has happened healthwise- what happened, not diagnosis
- Usual condition, skills, communication, what has changed
- Medications, medical notes, referral
- Name and contact for family/PR/SHA
- You and health professional on the same side of the patient

***Support Workers helping with
healthcare
(a) at hospital inpatients,
outpatients, emergency***

Famous bad mistakes

- Oh, I just met Tim today...
- Oh, are you a psychologist...
- Oh, I forgot the medications..
- Oh, what referral?....
- Oh, I can sign consent...
- Oh, I decided not to do that because I felt he should eat what he wanted to eat (patient with Prader Willi)...
- Oh, I cancelled that hospital appointment...

..and just as horrible doctor stories

- Well because she does not read it does not matter if she cannot see...
- Go and see that mentally retarded fellow...
- She has no quality of life...and we should not give any treatment..switch it off...
- It's veterinary medicine..
- There is no point in offering rehabilitation as they can't walk anyway ...

What you can expect on behalf of your client

- Professional attitude from health professionals
- Clear explanation of possible medical problems and tests-to and fro
- Follow up plan-Who does what, where and when
- Copy of correspondence to GP to patient at home

Team to prepare for hospital before it happens

- Consider risk of patient needing ambulance
- Logistics of Support Worker back up at home and in patient
- Acknowledgement of need for well known Support Worker
- Prepare ***Hospital Documentation***
 - Medications, Medical history, Contact, Patient as a Person (photo), Syndrome, Skills, Communication, Mobility, Sensory, Eating etc

....know about the hospital setting

- Outpatients, Inpatients-know ward, Emergency Department
- Junior Doctors and Senior Specialists-know names and specialty
- Nurses, Allied Health- know who is involved
- Ward rounds daily
- Hospital vs Community based resources
- Lost charts-bring *Hospital Documentation every time*

..know what Health Professionals need

- Docs need to know the accurate story of why here, to examine and do tests- they are not magicians-they need to know what happened
- They may not know much about syndromes, even Down syndrome, or medico-legal situation; most have had very little training about health or disability principles
- Include in *Hospital Documentation*

..know the patient as a person

- What is the person like when they are well
- The patient's usual skills, mobility, communication, well being, activity, medications, nutrition
- Why they are being referred and to whom
- Consent issues, medico legal issues
- Have *Hospital Documentation*

Inpatient care

- Well known Support Worker with patient
- Support Worker presence, needs, OHS
- Support Worker talks with Charge Nurse about their role- what they do and do not do
- Know name of doctors, ward rounds, can request appointment
- Know diagnosis, plan, discharge, what has to be done, copy of letters to home
- Add to *Hospital Documentation*

Outpatient care

- Well known Support Worker
- Prepare client
- Appointments, parking, who and why etc
- Prepare beforehand with usual team
- Bring all usual *Hospital Documentation*

Emergency

- Patient urgently unwell and when to call 000
- Be able to tell the story of what happened
- Extreme vulnerability
- Activate plan
- Well known Support Worker who can tell the story, bring usual *Hospital Documentation*

***Support Workers learning
more about healthcare
processes
(b) at home***

Follow up at home

- That letter has been filed...no, it's gone to head office
- Oh that was someone else who went..
- Oh that isn't my concern, I am not a doctor...
- Oh I cancelled that appointment....

After the appointment or inpatient stay

- Update rest of team at usual weekly meeting
- Feedback from rest of team on progress or new problems
- Raise question if further education or skills needed
- Clarify follow up plans
- If not sure first port of call is GP

Follow up at outpatients

- New doctor, charts lost, new staff, busy
- Brush off
- Don't leave the room unless you know what is going on!
 - Diagnosis
 - Plan of treatment
 - Letters to home, GP, family
 - Next appointment

***Support Workers helping
Health Professionals on
disability issues***

**Support Workers helping Health
Professionals on disability issues**

- Normalisation
- Least restriction
- Normal manners!
- Same treatment same condition- ask “Is this what you would have if you had the same condition”
- Support workers lead the way- talk with patient, dressing, behaviour, organisation, care, professionalism
- Support workers being assertive

Know about complaints mechanisms

- Local hospital resources
- Health Complaints Commission
- Ombudsman
- Advocacy
- Government
- Media

..back to the case

Example

- 34 year old single woman with cerebral palsy and moderate intellectual disability
- Lives in group home with 24 hour care
- High physical and practical needs, epilepsy, PEG nutrition, multiple medications, mobile on chair
- Communicates using vocalisation and some adapted makaton; continent with signing; anxious in new situations
- One weekend her PEG tube falls out

Thinking before the ..fan...

- This patient has a high risk of needing both inpatient, outpatient or emergency hospitalisation
- Behaviour risk
- Intellectual and speech disabilities
- Skills of Support Workers required
- Leadership by Support Workers required

Very vulnerable patient

Be prepared

How to prepare..

- **Patient**
 - Discuss health and hospitalisation possible needs in manner appropriate to level of disability
- **Hospital documentation ready**
 - Patient as a person, medications, medical notes, skills, physical and intellectual needs, photo when well, Person Responsible
- **Staffing organisation**
 - PEG care, seizure care at home vs hospital
 - Well known staff member who is able to tell the story; activate staffing organisation for group home

...in the emergency room

- Telling the story of what happened and usual well being of person- the PEG tube; ?any oral nutrition
- Providing background information in *Hospital Documentation*
- Calming the patient, Communicating with the patient
- Helping with examination, tests; advising doctor of ability to assist
- Names of doctors, what is going on, what is diagnosis, what is treatment; can we use the PEG straight away?

..in the ward as inpatient

- Name of ward, routine of ward, loos, kiosk
- Name of Consultant, Charge Nurse, shift nurse; clarify role of support worker eg not blood pressure but help to wash
- Communicate with patient about what is happening
- Make appointments with doctors
- How long stay there; bed, chair
- Diagnosis, management, discharge, follow up, information for home, request letters
- Do not hesitate to clarify, question, to be assertive on behalf of your client

...at home at usual weekly team meeting health section

- Make sure know what to do eg PEG management at home
- Discuss at team meeting; read and file hospital letters to team
- Clarify what questions; organise for answers
- Make sure everyone knows
- Progress of client
- How it all went; debrief; review home system of hospital care

..later on in outpatients

- Appointment time, parking, addressing fear and anxiety
- Name of consultant, name of specialty, why present
- Well known Support Worker
- Medications, medical chart, patient as a person..ie usual *Hospital documentation*
- What is going on
- Feedback to staff

case again.... continued

- Relief staff member calls ambulance
- Taken to hospital “the tube fell out”
- No person and no documentation to accompany her
- Left in ED for 10 hours in side room
- Became agitated, incontinent, no nutrition or usual medications given
- Sent home with the wrong tube *urinary catheter*; no PEG
- Had seizure at home, readmitted and nasogastric tube inserted, urinary catheter removed
- And readmitted a week later for PEG reinsertion under anaesthesia

Summary

- Support Workers have a role in leadership in healthcare for their clients
- Many adults with intellectual disability have medical problems requiring hospitalisation
- Vulnerable in this setting
- Patient, Support worker, Health Professionals, systems
- Anticipate, prepare, learn, care

...Summary continued

- Well known Support Worker
 - Knows what happened, assertive, truthful, prepared, aware of disability principles, helpful
 - Plan at home for organisation, education, weekly meeting updates on health
- Plus Hospital documentation
 - Patient as a person, skills, medications, medical notes, Person Responsible, syndrome, photo
- Plus leading the way in disability issues with care and professionalism

Thank you

SHAID* Clinics, Calvary Health Care Tasmania

, *Specialist Healthcare for Adults with Intellectual Disabilities

Individual health and support profile for adult patients with disabilities presenting to hospital

Basic information about patient (Carers to fill in)

Date filled in.....

Name and role of person filling this in.....

Name			
Date of birth			
Gender			
Address			
Phone number(s)			
Medicare number			
Private insurance			
Type of residence		Religion	
Statutory health attorney name/Person Responsible			
Address			
Phone number(s)			
Support agency			
Name of key person from agency			
Contact of key person			
GP name			
GP address			
GP phone			
Other main drs names and contacts			
24 hour emergency contact person			
Phone			

PHOTO OF PERSON WHEN THEY ARE WELL AND HAPPY

Patient's Manner, Skills and Function (Carers to fill in)

Date filled in.....

Name and role of person filling this in.....

Basic Information About Patient as a Person	
General manner	
Likes	
Dislikes	
Special friends	
Activities	
Safety concerns	
Cognitive status	
Family contact	

Baseline Information of Skills						
Type of residence (circle correct)	FAMILY HOME	GROUP HOME	INSTITUTION/ NURSING HOME	HOSTEL	OWN	OTHER
Mobility skills (circle correct)	INDEPENDENT --Steady --Unsteady	NEEDS ASSIST --1 person --2 person	MOBILITY AIDS --Walker --Stick	WHEELCHAIR	NON-AMBULATORY	
Dining/Eating (circle correct)	INDEPENDENT	NEEDS ASSIST	TOTALLY DEPENDENT	FED THROUGH A TUBE	OTHER	
Diet texture (circle correct)	STANDARD	CHOPPED/10c PIECE	MINCED	PUREED	THICKENED LIQUID	
Diet type (describe)						
Swallow risk (describe)						
Position for eating (describe)						
Vision (circle correct)	NORMAL	LOW VISION	BLIND	WEARS SPECTACLES	Comment	
Hearing (circle correct)	NORMAL	HARD OF HEARING	DEAF	HEARING AID	Comment	
Toileting ability (circle correct)	CONTINENT	NEEDS ASSIST OR PROMPTING TO GO	INCONTINENT	CATHETERISED	Comment (eg is there a bowel plan?)	
Medication administration (circle correct)	INDEPENDENT SELF MED	MEDICATION BY STAFF	SPECIAL FORMULATION eg liquid		Comment	
Communication (circle correct)	ABLE TO VERBALISE NEEDS AND UNDERSTAND WELL	SOME DIFFICULTY IN SPEECH; UNDERSTANDS BETTER	UNABLE TO SPEAK, USES FACE & BODY EXPRESSION	USES COMMUNICATION AID	Comment (eg what are the signs for yes and no)	
Posture and seating (describe)						
Washing and hygiene (circle correct)	INDEPENDENT	NEEDS SUPERVISION	TOTALLY DEPENDENT		Comment	
Other eg safety issues, sleep pattern (describe)	Eg cannot use call bell, needs strap for posture, not aware of water temperature, falls					

Medical history (Carers to fill in)

Date filled in.....

Name and role of person filling this in.....

Date	Condition	Management/Comment	Managing dr
	Cause of disability		
	Is it progressive or stable		
	Intellectual function		
	Musculoskeletal issues		
	Epilepsy		
	Other neurology		
	Gastrointestinal issues		
	Skin issues		
	Endocrine issues		
	Vision		
	Hearing		
	Cardiac issues		
	Respiratory issues		
	Dental issues		
	Reaction/recovery from anaesthetics		
	Immunisation: Fluvax		
	Pneumovax		
	Hepatitis B		
	Hepatitis A		
	Tetanus		
	Recent weight		
	Allergies		
	Family history		
	Ability to cope with tests		
Please fill in rest of any medical and surgical history below			
Special instructions for hospitalisation			

Preferred way of taking medications (describe).....

Current medication list, including prn (Date of writing this list.....)

Medication name	Dose of each single tablet	Breakfast dose	Lunch dose	Dinner dose	Bedtime dose
<i>Eg Bloggs</i>	<i>10 mg</i>	<i>2 tablets</i>	<i>1 tablet</i>	<i>1 ½ tablets</i>	<i>nil</i>

Tips to improve the hospital stay: I. Preparation by caregivers and support agency

Item to checklist	Yes/No (circle correct)	Comments
Awareness of caregiver well known to patient key role in providing history to health professionals	Yes/no	
Prior assessment of patient vulnerability and safety in hospital setting	Yes/no	
Assessment if patient needs 24 hour support in hospital because of distress, disability or behaviour needs	Yes/no	
Awareness that hospital staff will not provide 24 hour care to patient unless there are medical reasons	Yes/no	
Pre-hospital explicit clarification of resources to provide non-medical in-patient care by caregivers	Yes/no	
Awareness to have home-hospital documentation prepared and medication	Yes/no	
Awareness of role of advocacy but only Statutory Health Attorney can give consent	Yes/no	
Awareness of occupational health and safety concerns of work in hospital setting	Yes/no	
<u>Any other concerns in the hospital setting</u>	Yes/no	

Tips to improve the hospital stay: II. Information that caregivers should seek to obtain

Item to checklist	Yes/No (circle correct)	Comments
Date		
Hospital name		
Name of doctor in charge		
Diagnosis	Yes/No	Details
Inpatient management plan		Details
Inpatient meeting with doctors	Yes/No	Details
Inpatient meeting with charge nurse to clarify role of caregiver/family and nurses	Yes/No	Details
Discharge planning with treating medical team and transport needs; liaise with team	Yes/No	Details
Outpatient follow up plan	Yes/No	Details
Copy of letters to patient's home	Yes/No	No comment required
Notify treating doctors that copy of letters to go to the following doctors, nurses, statutory health attorney (have addresses handy):	Yes/No	No comment required
Have changes in medications been explained to patient and their caregivers; do you have a Green card?	Yes/No	Details
Discharge summary done	Yes/No	No comment required
Are there any changes for allied health team (names and contacts) eg speech therapist physiotherapist occupational therapist dietician nurse psychologist service agency These should be written down in discharge letter	Yes/No	Details
Next appointment	Yes/No	Details
Any comment on difficulties of the hospital stay?	Yes/No	Details

A/Prof Robyn Wallace, SHAID Clinics, Calvary Health Care Tasmania., R.Wallace@Calvarytas.com.au