

COMMUNICATION OF HEALTH CARE NEEDS PART 2

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*(*Specialist Healthcare for Adults with Intellectual Disabilities)*

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Case

- 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
- ...after 5 hours....became agitated, noisy, incontinent, no nutrition or usual medications given- “nuisance” to staff; junior doctor sent to attend



..continued

-after ten hours...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



Adult patients with intellectual disabilities in hospital setting



....high users of hospital level care

- Multiple medical problems per person; 3/4 of problems require specialist input (Beange 1998, Wallace 2011)
- Costs more, stay longer (Polder 2002, Birenbaum 1990)
- Constellation of negative health determinants impacts on health
- Present at late stage of illness, inadequate primary level care
- Syndrome related issues, epilepsy, pneumonia, us health problems, gastrointestinal, spasticity, equipment, dental, test under sedation



...and they are more vulnerable there

- Greater level of sickness at hospital
- More difficult to perform usual process of trade of history, examination, tests, diagnoses and management plans- proxy histories, behaviours, complex social situations, tricky medicine
- Barriers to optimal care at every level



...poor hospital care kills people..

Contributions to avoidable deaths (Kastner 1993)

- Lack of previous medical history or records
- Delays in diagnoses, missed diagnoses
- Non compliance with previous or new recommendations
- Parents or guardians choice between convenience of local medical care and the need for specialised care
- Patients behavioural problems complicating diagnostic and management
- Delay in management of acute condition (ie less aggressive management compared to patients without disabilities)
- Impaired communication between medical staff, patients, families, state agencies, group home etc regarding education patients condition , planning if care, follow up and coordination of services



...but good care seems to work

- Treatment of children with DS and congenital heart disease (CHD) have same life expectancy as those without CHD
- Medical care, allied healthcare, access to medical specialists, mortality profile more similar to general population eg cancers and cardiac disease (Crichton, 1995)
- Increased life expectancy in adults with cerebral palsy where good access and care from hospital, allied health, medication review, orthopedic care health promotion and full programme of social activities (Jancair 1996)



The *Patient's* role in their hospital level care



What the patient needs to know...

- Within their skills, about their health, about healthy living
- About hospital set up
- Support staff speaking positively, being confident, hospital not a punishment, driving by
- Reassurance, desensitisation works both ways
- About behaving well and having a positive attitude
- Ability to provide consent at times
- People with ID being volunteers in the hospital setting



In the Case...the patient

- Not sure she could have done more on her own on her own initiative....
- Communication aid containing hospital related themes
- But with assistance on pre-hospital preparation
 - more patient with waiting times
 - knowing the hospital processes
 - more confidence and less fear



What *doctors* need to know...



..a fair bit...

- “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 ...”



...about the medical

- Core business is the medical story
- No apologies-it is a different relationship compared to the support worker
 - Health history- current symptoms and past medical problems
 - Examination
 - Tests
 - Diagnoses
 - Treatment plan
 - Follow up



.. also about the patient

- The patient as a person and about their disabilities
- To insist on help from support staff when it is required, and communicate with them
- Home situation in working with the patient and their team
- Disability philosophies – same condition same treatment, least restrictive
- Logistics information: “person responsible” contact details, family doctor, medical files from home, old letters, medications, allergies
- Where to look things up



In the Case- the doctor

- Engaging with the patient as a person, and acknowledging her cognitive and motor disabilities
- Getting the true history, examination, tests, diagnoses, plan- insisting on well known support staff to help
- Not avoiding the patient, not guessing, but being reassuring, respecting disability principles
- Being aware of legal aspects
- Follow up: Addressing staff education re-what to do when the PEG falls out
- A type of ***hospital documentation*** and photo could have helped



Hospital documentation-up to date, brief and accurate

- Demographic details
- Likes and dislikes
- Skills (circle the box) in the hospital setting
- Health dot points
- Medications and allergies
- Action shot photo
- Plus-Past medical letters and info sheet on syndrome
- Plus-Pre-hospital preparation, Discharge preparation









What the *hospital* needs to do..

- Collaboration with disability sector-letting service providers and families know what the healthcare providers need and vice versa
- A culture of practical and enthusiastic acceptance of special needs of patients with intellectual disabilities
- Hospital volunteers with intellectual disabilities
- Legal aspects of consent, insurance
- Disability philosophies built into core business
- A plan for “difficult patients”
- A plan for complaints receipt
- Education program for students



Specialised service within generic services

- Optimal availability and accessibility to mainstream health services -More time, adequate support, no financial barriers, understandable information
- Health professional in mainstream services will have competencies in ID and therefore in some of the more specific health problems in people with ID-Training implications- students, registrars
- Health professionals who are specialised in the specific health needs of individuals with ID are available as backup to mainstream health services
- Promotion of disability philosophies, demonstration in case at grand rounds, usual quality assurance scrutiny



..in the Case...hospital...

- Overt policy of positive attitude towards adapting usual processes for patients with disabilities
- Review the case at morbidity rounds/audits
- Contact service provider- provide guidelines of what the hospital requires eg the responsibilities of the disability organisation and support staff, and what in turn patient can expect
- Initiate formal collaboration between health and disability sectors
- Take the initiative of ***hospital documentation*** preparation



What the *Service Provider* needs to know and do



..a fair bit...

- “Our funding ceases when the client goes to hospital”
- Denial of any role of medicine and health in the context of disability..”poo hoo to the medical model”
- “No medicine unless there is a behaviour problem”
- “we can’t do PEGs..it’s too invasive”..while attending to private and personal hygiene



Roles of service providers

- How health professionals and systems work
- That funding for care needs continues into the hospital setting for many patients
- Acknowledge the importance of health and take responsibility to educate its staff re health and health processes; Storage and dissemination of medical information to support staff
- ***For each client:*** hospitalisation plan of management before hospitalisation is required, ***hospital documentation***, discharge planning
- How to educate health professionals re disability principles of care



Pre-planning *admission* to hospital

- Hospital risk assessment for each client
 - What is the patient risk in the hospital setting- cognitive, behavioural
- Staff management
 - How can we activate a plan to ensure appropriate staff there and at home
 - Educate staff re hospital role
 - Ensure staff aware of legal issues, occ health and safety
- Awareness of hospital processes
 - Hospital will not provide 24 hour care for “behaviour” but should for medical reasons
 - What to take in for every appointment and how doctors do their trade
 - Ward rounds, consultants, registrars, interns, charge nurses, ward nurses,
- ***Hospital documentation*** preparation



Pre-planning *discharge* from hospital

- Staff support for what is required
 - What is the diagnosis
 - Who is the doctor
 - What are the medication changes
 - What to do and what not to do
 - Follow up appointment
 - Updating team at home
 - Documentation at home
 - Follow up on staff education matters
- Filing and dissemination of hospital information to support team



In the Case...re service provider

- Pre-hospital plan
 - Would have identified their client at “at risk”
 - Would have had a crisis plan for hospitalisation and staff needs and would have activated this
- ***Hospital documentation*** with photo
- Committed funding to support their client while in hospital
- Discharge plan
 - Prevention re-PEG education and liaison with gastro te



What the *Support Worker* needs to know



....a fair bit...

- “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...”



Support worker can save lives

- In the front line...and often give the story, help with examination, tests, hear the diagnosis and plan.
- Know the patient
- Know the reason for the presentation
- Set example in communication with patient and patient as a person
- What to bring for every appointment
- Role of advocacy, awareness of legal limitations
- ***Hospital documentation every time***



...in 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 and appointments
- Hospital vs Community based resources
- Parking, cafe, loos
- 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 disability principles
- Include in ***Hospital Documentation***



..know what the patient needs

- A truthful spokesperson
- An informed assertive professional
- Explanation and reassurance
- A prepared and confident support worker
- Brings ***hospital documentation***
- Informs the team back 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....



...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



..... about complaints mechanisms

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



..even so...pitfalls and perils

- This population and their carers rarely complain (Beange 1998)
 - 65% of the participants with intellectual disabilities reported no symptoms
 - 24% of the carers said there were no problems despite the mean 5.4 problems per patient
- Graded assertiveness
- Be honest
- Backup and question



Summary

- Adults with intellectual disabilities are high users of the hospital system and are vulnerable in this setting for many reasons
- Patients, health professionals, health systems, service providers, support workers each have complementary roles to play for optimal patient care...way beyond mere safety
- Prepare beforehand: patient preparation, staff preparation, documentation preparation, doctors, systems support
- Activate the plan and assist during inpatient
- Discharge and follow up plan



Achievable Case Progress

- The PEG falls out
- Patient already aware of possibility and need for hospital presentation
- Service provider already assessed this patient needs 24 hour support in hospital
- Regular staff called in to stay with patient
- Hospital documentation grabbed, meds
- ED waiting with confident staff and known support worker; no bladder accidents, importance of epilepsy meds stressed, ED staff offer patient and support staff cuppa
- Recognised as semi urgent case by triage nurse
- Doctor meets patient, given documentation, cooperative teamwork, obtains history, examines patient, makes diagnosis and plan
- Explains to insert new tube which is done; medications given
- Support worker asks to have copy of letter and recommendations to avoid
- Follow up- how to manage this emergency at home
- Patient goes home within 3 hours
- Support worker feeds back to rest of staff at usual team meeting

Thank you

