

You can go home now.

Supporting the family with a child who needs complex care at home.

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Fellow, abpn.

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Background

Mark, now aged 17 years lives with his middle-aged parents and has two older brothers, both of whom have had serious health issues themselves. Mark was born with pre delivery diagnosis of Global Developmental Delay, he is classified as

- non verbal
- having severe bilateral visual impairment (blind) but does not like being in dark environments
- Suffering with Epilepsy – has a Vagal Nerve Stimulator (VNS) in situ
- non weight bearing
- unable to swallow, so Nil by Mouth except emergency medication for seizures, requires very frequent and often urgent oral pharyngeal aspiration with either saliva or phlegm if coughs
- needing to be kept well hydrated and fed through Gastric Peg tube
- having sluggish bowel so has twice daily passage of flatus tube to relieve gaseous distension
- having poor upper body muscle power, so can not raise arms and has contractures affecting both hands
- Unable to move any limbs voluntarily so requires repositioning to prevent pressure sores
- Mouth breathing necessitating frequent oral hygiene to prevent fungal infections
- Still having infant teeth as well as adult teeth, so he has overcrowding of teeth and gum soreness
- Needing SEND support so attends school when his health permits to socialize
- transitioning from Children's to Adult care Services .

Daily routine

Time	Aspects of care
0600	Stop overnight feed and administer medications vis Gastric Peg tube with 60 mls water flush
0620	Perform flatus procedure
0635	Wash and dress
0645	Medications with 60 mls water flush
0745	90 mls feed with 15 mls water flush pre and post
0745	Administer Colomycin nebuliser
0810	Medications with 60 mls water flush
1000	90 mls feed with 15 mls water flush pre and post
1100	Medications with 60 mls water flush
1100	N / Saline nebuliser

Daily routine continued

Time	Aspects of care
1200	90 mls feed with 15 mls water flush pre and post
1300	Medications with 60 mls water flush
1400	Medications with 60 mls water flush
1445	90 mls feed with 15 mls water flush pre and post
1445	N / Saline nebuliser
1545	60 mls water flush
1645	Medications with 60 mls water flush
1700	Bath in spa bath
1800	Perform flatus procedure
1845	Medications with 60 mls water flush
1945	Medications with 60 mls water flush
2045	Medications with 60 mls water flush then commence overnight feed
2105	Open Farrell Valve for overnight feed

Medications

Drug	Format	Route of administration
Colomycin	Dry powder vial to be mixed with N/Saline	Nebuliser
Buscopan	Tablet diluted in water and dose calculated	via Peg
Clobazam	Liquid drawn into syringe	via Peg
Gabapentin	Liquid drawn into syringe	via Peg
Carbamazepine	Liquid drawn into syringe	via Peg
Levomepromazine	Liquid drawn into syringe	via Peg
Senna	Liquid drawn into syringe	via Peg
Clonidine	Tablet diluted in water and dose calculated	via Peg
Lansoprazole	Liquid drawn into syringe	via Peg
Baclofen	Tablet diluted in water and dose calculated	
Phenobarbital	Liquid drawn into syringe	via Peg
Cenobamate	Liquid drawn into syringe	via Peg
Saline	Plastic vials 0.9 or 3%	Nebuliser
Midazolam	Syringe	Buccal for prolonged seizures
Paracetamol	Liquid	Syringe – as required – who decides?

Aspects Discussed with family		Yes	No	N/A	Comments
Medication	Reason for using				
	Format				Often adult format supplied
	Dosage				
	Route of admin				
	Safe storage				
	New prescription ordering				
	Provision /replacement of sharps bin				
	Safe collection of full sharps bin				
	Safe disposal of glass vials				
Syringes	Sizes needed				
	Ordering				
	Storage				
	Disposal				
Feeding	Ordering and safe storage of Peg sets				
	Feeding bottles				
	Farel Valve sets				
	Safe disposal of items				

Family support continued

	Aspects Discussed with family	Yes	No	N/A	Comments
Oxygen	Prescription source and review				
	Storage and administration				
	Recording and reordering use				
Suction	Type of catheter to use				
	Storage and reordering of equipment				
	Filters and machine Cleansing				
	PAT testing				
Record keeping	Seizure type, duration and frequency				
	Vagal Nerve Stimulator training and use				
	Appointments / Tests /scans				
	Clinical observations (TPR, Sats)				
Positioning / Moving and handling	Hoist training				
	Sling size and type				
	Sling care				
	Wheelchair care / maintenance				

	Aspects Discussed with family	Yes	No	N/A	Comments
Infection control	Provision of P. P. E.				
	Ordering and storage of items				
	Disposal				
	Carer training and record keeping				
Moving and handling	Size of Hoist slings				
	Hygienic care / Replacement				
	PAT testing				
	Safe training reviews				
Bowel care	Size of Flatus tubes				
	Syringe size				
	Procedure training				
	Type and volume of fluid to be injected				
	Temperature of fluid injected				
	Volume of fluid to be injected				
Record keeping	Seizure type, duration, resolution				
	VNS management and staff training				
	Emergency Medication - Midazolam				

Key questions

Whilst in hospital, family have to stay all the time as Nurses always ask the family to manage all his medications and drug security. Is that safe practice?

Who is responsible for family support – fluids / food / hygiene care / resting facilities?

Who decides when the parents are “fit” to take Mark home when they are so tired?

Who assists ensuring Mobility vehicle safe, insured and carer trained as patient escort?

Who is “Professional Lead” for transitioning to ensure

- Referral to Gastroenterologist (flatus procedure)
 - Dietician (calorie management)
 - Physiotherapy / Respiratory team (Oxygen prescription not updated for over 10 years)
 - Neurologist
 - Continence Team
 - Pharmacist
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- Where might the family get respite care from?
 - Who organises and pays for carer training in Adult Services?

Personal Preferences / concerns

- Why is Holistic approach to care no longer promoted / apparent?
I like to apply Activities of Living Model, Roper, Logan and Tierney, 2000 to ensure when 24-hour care is planned and delivered all aspects of life are considered for both young person and family.
- Why do many adult clients feel they are regarded as Disease Units and not a person?
- Why are Specialist Nurses not available 24 / 7?
- How do we ensure clinical observations and nursing skills are not diluted and our Registration status is more fully appreciated, promoted and protected?
- What has happened to family support from Community Children's Nurses especially where child is transitioning to adult services?
- How does young adult secure Community Nursing support?
- Thank you, keep yourself and all clients safe and enjoy your future career.