

Home Management (when management changes are needed & sick day modifications)



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Medications



Do I have enough in date supply?



Do I know how much to administer?



Do I know how to administer?



Do I know how to store?



Do I know who is prescribing?

Feeds

Does my child require carbohydrate supplements? In what form (glucose polymers, high energy formula, pre-term formula, breast milk fortifier)?

Do I need scales to measure glucose polymer?

Do I need a feeding pump? How many?

How frequently do I have to feed my child?

What type of food do I have to offer carefully?

Do I need to give slow release carbohydrates such as uncooked corn starch?



Tips to avoid oral aversion

 Follow the baby's signals about what time to feed

 Feed promptly when the baby is hungry

 Hold the baby securely so you can look at each other during feeding. Let the baby decide how much to have

 Let the baby pause, rest, socialize, and go back to eating

 Don't disrupt feeding

 Stop the feeding when the baby refuses

 Follow physiotherapy/occupational therapist guidance if there are mobility concerns

 Dummy dipping with breast milk, water or formula

 Minimising repeated, painful or uncomfortable touches around their face e.g. tape is removed or reapplied

 Use of positive touch that comforts and gives pleasure - kiss, stroke & touch

Blood glucose monitoring



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What type? Glucometer, CGM



Which device? Learn how & when to use it



What equipment do I need? glucose strips, lancets sensors, receiver



How frequently? Agree an ongoing monitoring plan. Pre-meals & bedtime, if symptomatic or unwell



What is the target? How many times do I have to check if it is low?



How do I store the data?

SYMPTOMS



SHAKING



SWEATING



ANXIOUS



DIZZINESS



HUNGER



FAST HEARDBEAT



IMPAIRED VISION



WEAKNESS
FATIGUE



HEADACHE



IRRITABLE

Asymptomatic

Written emergency hypoplan

Training for glucagon injection

Emergency treatment

Product	Age of patient	Hypo management (glucose in gram)
<u>Glucogel</u> (10g glucose/ tube)	Neonate-6 months	1/3 rd tube 3.33g
	6 months-2 years	½ tube 5g
	2-5 years	1 tube 10g
	>5 years	1 ½ tube 15g
<u>Gluc juice</u> (15g glucose in 60mls)	2-5 years	40mls (10g)
	>5 years	60mls (15g)
Glucose tablet (4g glucose)	2 -5 years	2 ½ tabs (10g)
	>5 years	4 tabs (16g)



Emergency Regimens (Illness plans)



An ER is a feeding plan, used during intercurrent illness for patients who are at risk of Hypoglycaemia



When is it given?

Intercurrent infections, fever
Reduced appetite, food or feed
Vomiting, diarrhea



Standard ER is a glucose polymer solution (10,15,20 25% CHO) concentration dependant on age, given at 2-3hourly intervals day and night



Volume based on normal fluid requirements for age

Open access/shared care with your local pediatric team

School

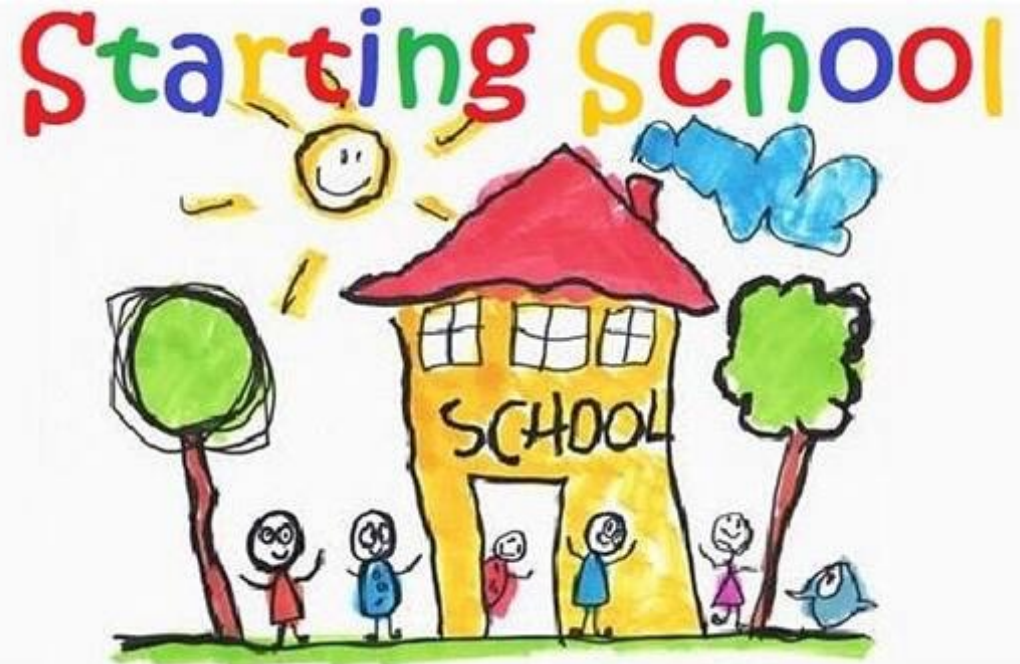
Who will check the BGs? Have they been trained?

How frequently to check BGs?

Emergency hypoplan training of the carers at school

Snacks for activity

Emergency contacts



Outpatient follow up

Regular follow up visits to
advise standard of care
adjustment if needed



Role of Clinical Nurse Specialist for Home Management



- Educate children and families about the complex condition
- Accompany families on their journey through communication, collaboration, and coordinated care
- Support and empower parents to maintain their children's health at home, reducing hospital admissions
- Serve as the point of contact when at home
- Liaise with local services (nurseries, schools, other healthcare providers)

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