

# MY PERSONAL CENTERED PLAN

Insert my name here

Insert photo of me here

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# My Person Centred Plan

## Dates

Date when plan was first written: **Date**

Dates when the plan was updated:

Date Updated	Changes made to this plan
<b>Date</b>	<b>Changes</b>

## What I hope this plan will accomplish for me

- Acknowledge and celebrate the good things in my life
- Help people who are involved in my support to understand the ethos of my lifestyle
- Help people who are involved in my support to understand the family structure and values
- Highlight some of the areas in my life that can be improved and thus make things better for me

## People involved with making this plan

Who helped with this plan?

**Insert names here and their role in my life, e.g. parent, friend**

**Insert names here and their role in my life, e.g. parent, friend**

Who provided information?

**Insert names here and their role in my life, e.g. parent, friend**

**Insert names here and their role in my life, e.g. parent, friend**

Other people involved in my care

Insert names here and their role in my life, e.g. parent, friend

Insert names here and their role in my life, e.g. parent, friend

Insert names here and their role in my life, e.g. parent, friend

## Important Information About Me

### Name and address

Hello, my name is: **name**

I was born on: **date**

I like to be called: **name**

My home address is:

**address**

### Contact numbers and emails

Home telephone number: **number**

Mobile telephone numbers:

**Number and name of who will answer**

**Number and name of who will answer**

Email addresses:

**Number and name of who will receive the email**

**Number and name of who will receive the email**

### Important people in my life

**Name, their relationship to me, their telephone number and email**

**Name, their relationship to me, their telephone number and email**

**Name, their relationship to me, their telephone number and email**

**Name, their relationship to me, their telephone number and email**

### Allergies (Medication to avoid)

**Insert names of medications and foods here**

Name and address of my GP

Name, surgery address, their telephone number and email

Important medical information

*Main conditions*

Add conditions

Examples:

- CHROMOSOME ABNORMALITY FROM BIRTH PARTIAL TRISOMY 11 PARTIAL MONOSOMY 10
- VENTRICULAR SEPTAL DEFECT AT BIRTH (CLOSED ON OWN)
- EPILEPSY
- OSTEOPOROSIS
- COXA VARA (DEFORMITY OF HIP)
- CONGENITAL URETHRA STRICTURE
- VESICOSTOMY (SURGICAL OPENING FROM THE BLADDER TO THE ABDOMAN)
- KIDNEY DYSPLASIA
- REFLUX
- RECURRENT CHEST INFECTIONS
- URINE INFECTIONS
- SCOLIOSIS OF THE SPINE IN LUMBER AREA (77 DEGREE AT PRESENT)
- SEVERELY DISABLED
- CLUB FEET
- HEARING IMPAIRMENT
- SEVERE FEEDING DIFFICULTIES
- REGISTERED BLIND
- GASTROSTOMY
- DOUBLE INCONTINENCE

## Regular medication

### EXAMPLES BELOW

NAME OF MEDICATION	STRENGTH	DOSAGE	TIME
TEGRETOL Broken in half, <b>not crushed</b>	200mg per Tablet	200mg Tablet	Breakfast
		200mg Tablet	Tea
VIGABATRIN SACHETS <b>Not to be Mixed with water</b>	500mg	500mg	Breakfast
		500mg	Tea
DALIVIT DROPS		14 Drops	Breakfast Only Add to Weetabix
FULTIUM CAPSULES <b>Not crushed</b> , place on food		1 Capsule	Breakfast Only
CETRABAN CREAM FOR NECK AND BODY			Apply when required Daily
DOUBLEBASE EMOLLIENT GEL		Used for Washing	Morning/Evening
MACROGOL Name may vary	See Note	1 x 13.7g Sachet	Breakfast Only
CALSHAKE	See Note	1 Third Sachet	Breakfast Only
GLYCOPYRRONIUM BROMIDE Broken in half, <b>not crushed</b>	2mg per Tablet	2 mg Tablet	Breakfast
		2 mg Tablet	Dinner
		2 mg Tablet	Tea
MAXITROL EYE OINTMENT		In each eye	Morning Only
LEVOTHYROXINE	25mg Tablet	25mg Tablet	Morning Only
FRESUBIN	2 kcal Fibre	200ml	Dinner Only

TEGRETOL, VIGABATRIN, GLYCOPYRRONIUM, FULTIUM & LEVOTHYROXINE IS PLACED ON A SMALL AMOUNT OF FOOD AND GIVEN BY SPOON AT BEGINNING OF MEAL.

DALIVIT DROPS TO BE ADDED TO WEETABIX (BREAKFAST TIME ONLY)

CALSHAKE & MACROGOL ADDED TO 250ML OF TAP WATER, MIXED THEN ADDED TO BOTTLE, PLUS A FURTHER 250ML CALSHAKE ONLY (This replaces my morning milk drink only)

Add Macrolog first, then Calshake, shake container well before adding to bottle.

NOTE: ALL MEDICATION MUST BE GIVEN AT START OF MY MEALS.

*Further medication as and when required*

**EXAMPLES BELOW**

NAME OF MEDICATION	STRENGTH	DOSAGE	TIME
BUCCOLAM (midazolam)	10mg	2ml ORALY PRE-FILLED ORAL SYRINGE	Breakfast

BUCCOLAM is given by squirting half the prescribed dose between the lower gums and cheek on one side of the mouth, the remaining dose to the opposite side of the mouth. (Further instructions are in Epistat box). **DO NOT COMBINE THIS DRUG WITH DIAZEPAM.**

A second dose of BUCCOLAM (midazolam) must not be given within 8 hours of last dose. Contact my doctor or hospital before giving any further dosages.



## Seizures

If I show signs of a fit, talking to me and stroking my face will sometimes bring me out of a seizure before it gets worse. If I have generalised jerking, lasting more than 5 minutes then I will need Buccolam, if after a few minutes of having my Buccolam I don't stop fitting and I am breathless, call a doctor or 999

### *Signs of a seizure*

The first sign of a seizure

- My skin looks pale/feels cold
- My eyes roll up and are fixed
- I may cough and sound congested
- I may foam at the mouth, my jaw may move
- I may have bitten his tongue
- I may shake and go rigid

## Food

*Some of my favourite food I like and how I like it.*

Vegetables – Cauliflower, Broccoli, Carrots, Potatoes, Cabbage.

Meats – Chicken, Beef, Ham, Pork, Lamb, Liver Pate, Corned Beef, Meat Balls/Faggots, Chunky Soups, Fish.

Cheese Sauce, Parsley Sauce, gravy etc can be added to the above.

Puddings – Sponge/Custard, Creamed rice pudding, Trifle, Semolina, Angel Delight, Banana/Custard, Apple Crumble.

Weetabix, Porridge.

*Please remember how to prepare and serve my food*

All my meals need to be modified so that they are soft enough to be thoroughly mashed/blended and are moist enough so that the food drops off my spoon slowly. Time must be taken when feeding me, give me drink's regular throughout my meal, this will help clear my mouth. I can be very slow and sometimes uncooperative at times, so please be patient with me; sometimes just lifting my head up will help encourage me with my eating.

I tend to mess about with newer people who feed me; I need consistency (same person).

I can't eat any food that is very hot, also I only need my milk in the microwave for 10 seconds, just the chill removed (I'm a very fussy person when it comes to eating/drinking)

After I have eaten I must remain in my comfy chair for a least 2 hours, or I will be sick.

## *Breakfast*

I have two Weetabix mashed up with hot water, and then a small amount of cold milk is added, allow to cool so it's not hot for me.

I have 1/3 sachet of Calshake with 1 sachet of Macrogol added and mixed together in 9 fl oz water. Once I have had that, I then have 9 fl oz of semi skimmed milk in my bottle, with the chill taken off. Please don't over warm the bottle if microwaved (10 sec max).

If I am ill and refusing my meals/drink then I will need 200ml bottle of Fresubin plus 150ml of room temperature water via Gastrostomy.

## *Lunch time*

200ml Fresubin plus 200ml tap water (Mixed) then to be given via gastrostomy.

### *Tea time*

Vegetables, meat & potatoes must be cut and mashed up so I can eat them.

I have butter and a little milk added to my veg/meat/potatoes, this gives it a creamy taste, which I like. You can also add either a sauce or gravy.

My puddings are also mashed up, as I cannot eat any lumpy food.

Milk for dinner 18 fl oz with chill taken off.

If I am ill and refusing my meals/drink then I will need 200ml bottle of Fresubin plus 150ml of water via gastrostomy.

## More About Me!

### The ordinary things that happen in my life

#### *Sleeping - care at night*

I go to bed between 9.30-10.30pm (I need to remain upright for at least 2-3 hours after each meal, as I am prone to vomiting).

I wear a pad, pyjamas and (socks in very cold weather). All my tops will need tucking into my trousers to help prevent me from scratching my Vesicostomy/Gastrostomy. I lie on my back, I have one pillow with a towel placed over it and the surplus under the pillow because I dribble a lot throughout the night, this will need to be changed if wet to prevent my face and neck from becoming sore.

I MUST HAVE my arms placed outside the bed covers/quilt and the covers/quilt firmly tucked down the sides of the bed. Do not over wrap me in bed, or overheat the room, as this could cause me to have a seizure.

I have a special sleep system, which is for supporting my body, and spine, which is incorporated, into my bedding; full instructions and pictures are at the end of this Plan.

I enjoy some soothing music to go to sleep, only leave the music on for 10-15 mins. I often make noises and shout before falling to sleep. Please have intercom on when I am in bed.

I can have seizures during the night, therefore I will need to be checked regularly through the night as I rarely make any sounds, also I vomit on occasions and could choke.

During the last year I have had a lot of recurrent chest infections and during the night I cough and choke so I will need to be in a slight elevated position with constant supervision.

I sleep with the bedroom light off, and the bedroom door needs to be left quarter open. If I awaken during the night I will need my pad checking, as I maybe wet through or soiled. If I don't settle I may need some soft music or putting into my wheelchair with my tray and a few toys.

### *Waking Up*

I usually wake up between 7-8am, if I'm awake please get me up, if I am still asleep at 8am then please gently wake me. I will need a good wash all over (NOT ON MY BED), more so around my vesicostomy. No soap to be used on the face (plain water only). I must be prevented from scratching anywhere, especially my vesicostomy as it will cause a urine infection and make it bleed which may cause the opening to close then preventing me from passing urine, also prevent me from putting my hands in my pad, as I often poke my eyes and ears which in turn causes infections.

I am then dressed. All tops to be tucked in trousers. I don't wear shoes in the house, only when going out. I will need my bibs on and changed regular when wet; I wear 3 at a time (1 large, 2 small) due to constant dribbling.

I am then put into my wheelchair and fastened in, using lap strap, and harness. I do NOT need any shoes on whilst indoors, my feet can be placed on a pillow if needed, then put my tray on. See photos at the end of this Plan.

### *Pads*

When changing my pads, please ensure the back and front are folded down to avoid the plastic against my skin (to avoid skin irritation).

INSERT PHOTO

Pads turned over here at front and rear. (design may vary)

### *Meal times*

I need to sit in my wheelchair for all my meals, in the upright position. I need to remain upright for at least 2-3 hours after each meal, as I am prone to vomiting.

### *Eating*

I need time and patience to eat my meals as I sometimes experiences difficulty in swallowing – taking up to half an hour or more. I use a small flexible spoon (not metal). I have my milk during my feeds but save half my drink which can be given after I've finished eating. I may refuse my savoury meals but keep trying, as I will eat it eventually. If unwell and refusing my feeds I will need a bottle of my Fresubin via Gastrostomy please see the Medication section.

### *Drinking*

I drink all my fluids from my baby bottle; I have my own bottle and teats, as I will not use any other teats. (Please keep my own bottle and teats separate from others so not to lose them). Semi-skimmed milk is my favourite, and my milk must have the chill taken off, about 10 seconds in a microwave. I like to hold my bottle myself but will need help as I often drop it.

### *Breakfast (8AM)*

2 Weetabix, mixing with boiling water and sugar and cold milk to take heat out. (Will need testing for heat before giving). Another alternative to Weetabix is Ready Brek made up with milk and sugar.

Calshake (a third of the Sachet) & Movical (13.8g) added to 9fl oz tap water, then 9fl oz of semi skimmed milk (10 sec in microwave) still needs to be cool, as I don't like warm drink.

If unwell and refusing feeds please give 200ml Fresubin and 150ml of room temperature water via Gastrostomy.

I need medication with my breakfast.

### *Mid morning (10AM)*

I will need to be offered a drink of Juice between breakfast and dinnertime, in my bottle.

### *Lunch (12 Noon)*

200ml Fresubin plus 200ml tap water (Mixed) then to be given via Gastrostomy

I will need my medication at the start of my lunch (Small Yoghurt)

#### *Afternoon drink (3PM)*

I can be offered a drink of Juice in my bottle about 5fl oz.

#### *Tea time (5.30PM)*

My vegetables need to be well cooked, so they can be mashed easily with a fork, some vegetables with an outer shell will need blending, mash the potatoes, carrots, swede, cauliflower, broccoli etc, with a fork, adding butter and milk. If any meat is given this will need to be blended so very little lumps are visible, I don't like dry foods so cheese sauces or gravy to be added.

I like puddings, semolina, rice puddings, sponge and custard, preferable not chocolate as this can make me sick. I like yoghurts, mousse and jelly (but with the chill slightly taken off).

I also have 18fl oz of milk in my own bottle (chill taken off 10 seconds in microwave). I do sometimes take my meals slowly, so time is needed with me. Milk to be given during my meal, with at least half a bottle after my food.

If I mess about with my savoury food, please be patient as I will eat it eventually.

If unwell and refusing my feeds please give 200ml Fresubin and 200ml of room temperature water via Gastrostomy

I will need my medication at the start of my tea.

See earlier section regarding preparation of my food.

## Personal hygiene

I have a bath every other evening 2-3 hours after his tea. I have my own bath sling and toiletries with me, no soap to be used on my face.

At all times prevent me from scratching my Vesicostomy/Gastrostomy.

I have my his hair washed every other night.

I have my pads changed before all my meals, just before bedtime and other times when needed.

I dribble copiously and needs to wear 3 bibs at all times except bed time (Large first then 2 smaller bibs). Use Cetaban cream to protect against skin breakdown around my neck.

I need his teeth cleaning morning/evening if I will allow you.

If the skin around my Vesicostomy is sore, please use my barrier cream around effected area and get a urine sample taken.

Keep the area clean and dry around my Gastrostomy site using unscented baby wipes or clean flannel.

## Mobility

I use my wheelchair for outside and transportation only.

I have a stair climber to get up/down stairs. USED BY MY PARENTS ONLY

I use a JCM Jupiter chair for indoors with tray.

I use ceiling hoists throughout the home, blue special sling for bathing and black comfort recline (dry sling).

I have a bed system in place for my scoliosis.

Roll out Propad mat for floor play/physio and Dora leg wedge.

I also have Kingscraft padded bath sides, high low electric bath and changing bench.

## Playtime

I use my tray which fixes to my Jupiter chair (must be used - see photo later) to play with some toys.

I do put objects in my mouth, so care must be taken to ensure no sharp, small and protruding edges.



I relax and lay on my Propad Mat 2-3 hours after I have eaten. Place me on my back with a support under my legs (Dora Wedge). I will also need a small support under my left-hand side of my hip to keep my spine straight, i.e. a rolled towel.

## Communication

On occasions I say Mamma, Dada, Babba, No, Ahah, Yeh.

I get “mardy” when I need attention and I scream and shout if I’ve done a poo.

If I should cry, then maybe I’m ill or in pain.

## Being happy

I am a happy lad, affectionate and very sociable.

I have a sense of humour and love to giggle, especially when spoken to.

I love the company of other adults and children.

I love to be cuddled.

## Being sad

I am rarely sad but will get grumpy when bored! I love new activities to be offered, or a change of scene.

## General Information

I need to be stopped from poking my eyes, ears and nose. Also stop me from chewing my fingers and bending them. I also need to be stopped from scratching my neck, Vesicostomy, Gastrostomy and any other bodily area as this will cause me much soreness and infection. I will need to be stopped from pushing my bibs or any part of clothing into my mouth as this cause’s me to choke or be sick.

## Favourite Things – My Likes & Dislikes

### *Things I Like*

- Milk, Wheetabix
- Swimming in hydrotherapy pools
- Going on holidays/days out
- Doing things in my own time
- Others understanding my communication
- Others including me in conversations (even though I can't speak back)
- Having visitors (familiar faces)
- Dropping objects e.g. throw my toys on floor for someone else to pick up
- Music, cartoons on T.V, things with bright colours
- Bath time
- Visiting my family
- Going for walks (well, Mum & Dad take me in my wheelchair)
- Familiar faces, regular support staff
- Having my back, neck, legs and arms massaged
- Eating good food (vegetables)
- Being clean and tidy
- Playing with Mum or Dad
- Relaxation music
- Animal parks and zoo's
- Keeping Mum and Dad awake through the night while I'm having fun
- Theatres/live music/cinema/bowling

### *Things I Don't Like*

- Hot drinks and sour juices, (I'm fussy what I drink)
- Being rushed
- Not knowing what is happening
- Being ignored
- People not understanding what I want
- Too many people in the house at one time (strangers)
- Too much noise
- People talking when I am listening to my music
- Having my teeth cleaned, I hate it
- Coming home when I have had a 'fun time' out
- Hard lumpy food
- Constant changes in support staff who are not familiar with my routines and communication
- Being given food or drink too quickly

*Things I need to do on a daily basis*

- Take my medication
- Have a wash or bath
- Wash my hair
- Clean my teeth
- Have some form of exercise e.g. lay on my mat to stretch my legs and do my Physio daily routine.
- Drink and eat good meals
- Go for a poo (but this doesn't always happen)
- Get out in the fresh air (even if only for a short period)
- Have some fun time
- Play with my multisensory toys/lights
- Getting out in the community

*Things I must not do and the reason why!*

- Poke my eyes - they get sore, cause infections and they look a mess
- Poke my ears - they get sore, cause infections
- Bite my fingers – causes cuts, soreness and transmits infections
- Put my finger up my nose – transmits infections, soreness and it's not nice
- Scratch my neck – soreness, dryness, cuts, which leads to visits to doctors
- Scratch my Vesicostomy – infections, soreness, wet clothes, swelling which then stops me going for a wee, causing me much discomfort
- Putting my hands in my pad – dirty, infections
- Putting my bibs in my mouth – could make me sick, choke, get infections
- Mess about with my meals – causes mouth ulcers, which makes eating painful, then I get run-down, lose weight and become ill
- Shout and giggle all night – it keeps mum and dad awake
- Sleep during the day – I will not sleep at bedtime
- Hit myself with toys – causes bruising, bumps etc
- Scratch my bum – causes soreness
- Bend my fingers back – causes long term damage.
- Interfere with my Gastrostomy as I may pull it out or cause infection.

## About Me and My Life

### How you should see me

I would really like people to see me as a person and not just see my disabilities. People who know me think I have lots of gifts and qualities and these are some of the nice things they have said about me:

- He is fun to be with
- He is adventurous with his food, enjoys different things, but nothing lumpy
- He is good company
- He enjoys being with familiar people
- He is adventurous and enjoys new experiences
- He knows what he wants, but can't tell you
- He's a happy person
- He loves all animals, especially dogs and cats
- He enjoys all kinds of music
- He has great strength of character
- He enjoys the simple things in life
- He is able to show happiness when he is enjoying himself (laughing)
- He has a naughty sense of humour
- He enjoys sensual experiences such as massage, soft lights and music
- He is able to accept change, but in his own time
- He has a cheeky smile
- He is a cuddly person and very affectionate
- He enjoys the Cinema, concerts, theatre, zoo's, attractions.

## Things that are important to me now

We all thought about the things that are important to me now, and these are the things that we agreed I need to have or do, to be happy:

- My family is very important to me. I like it when they make me laugh.
- It is very important for me to have a stable and happy team of support workers whom I like and who know how to deal confidently with my complex needs.
- I am happiest when there is a clear routine; I like to know what is happening and what to expect.
- I am happiest with people whom I feel understand me, like me and prepared to be patient with me.
- I like my life to be calm, stable and moving at my own pace.
- I like people to explain to me what they are going to do. I don't like it when I don't understand what is happening.
- People need to stay calm and patient, as I may get upset if people shout at me or sound irritated.
- I enjoy having plenty of things to do and places to go. I like going out and particularly enjoy things involving animals.
- I enjoy going bowling, cinema, concerts, theatre, animal parks/zoo and many other attractions I have visited over the years.

### *Holidays*

I have recently started attending the local Day Centre. I have employed a 1:1 called Nathan who cares for me, I enjoy going here and I have settled in very well.

Swimming: I would love to do this but unfortunately there is no access in my area, as I need a hydro pool with changing bench and hoist.

Please add any additional thoughts, comments or suggestions about things that are important to me now:

## Things that are important to me for the future

Then we all thought about the things that will be important for me in the future. These are the things that I need everyone to help me achieve:

- I need to have a stable team of support workers whom I like and who understand me and are able to fulfil my needs.
- I need regular and ongoing input from therapy services that is relevant, progressive and recognises my needs.
- I would like to be able to go swimming regularly again.
- I would like to try to improve my general health.
- I want to maintain the contact I have with my family.
- I would like to widen my circle of friends, interests and activities.
- I would like to lead as normal a life as possible and for everyone to help me do the everyday 'normal' things that others take for granted.
- I would like to stay happy, comfortable, content and free from unnecessary stress.
- I want to live in an environment where I can feel relaxed and accepted.
- I would like to remain in my home with Mum & Dad with all the supportive aids and equipment necessary to ensure I stay safe, healthy and mobile.
- I want to continue going out in the community.

Please add any additional thoughts, comments or suggestions about what is important for me in the future.



## Important things you need to know

Because I can't tell you myself about how to support me and keep me healthy and safe, everybody has helped to make this list of some of the important things you will need to know:

- I communicate by gesture, eye-pointing and a few noises. You need to understand and respond to my non-verbal communication. You must open your mind to alternative ways of communicating and become extremely observant. Every look and movement can be a form of communication.
- When you need to give me food, make sure it's not hot, as I don't like hot food, just a bit beyond warm. I do not like hot drinks or very cold drinks (just chill taken off). Make mealtime a happy time as I take a long time to eat my food. Do not rush me, please be patient.
- If I don't feel well I may not eat my meal, but I might eat two Weetabix with warm water, milk and a little sugar. Alternatively, I may eat Ready Brek.
- I like milk with the chill taken off. I won't have hot nor very cold drinks.
- You must come to know and respect my likes and dislikes and allow these to shape my daily life and activities.
- Do not think you know best – ASK ME and give me time to respond. If you feel the need to override my wishes explain why to me and try to persuade me first. I am usually easy going, but sometimes I can be very awkward (at meal times).
- Do not bully me – I can indicate what I wish to do and when, but you must be prepared to learn the looks and know when I'm just awkward or when I really don't want something.
- A little humour makes me laugh and this can break the ice if I am in a bad mood, so be prepared to be silly!
- I need you to be kind, gentle and never to rush me.
- Explain to me what is about to happen e.g. having teeth cleaned, I will try and stop you cleaning my teeth, but you need to carefully persist.
- I enjoy long walks (in my wheelchair), car journeys and I especially love to get out of my chair and lay on my mat to stretch my legs.
- I particularly like relaxation music, e.g. ocean waves, whale sounds.
- I love going on holiday and having days out visiting the seaside and attractions.

## Important things to keep my healthy and safe

These are some of the things you need to do to keep me healthy and safe:

- Occasionally I can get low and run-down: at these times my physical and mental health needs to be considered, sometimes just a good meal and an early night's sleep will pick me up to my usual self.
- I use a wheelchair but I can't propel myself, so will need help from others.
- I need to have my wheelchair at all times when I'm away from my home, unless a suitable comfort chair is available when I am indoors (my wheelchair is for transportation and outdoor use only). My lap strap, chest harness should be fastened at all times. Tray to be used at all times.
- For safety reasons I use a hoist for accessing my bed, wheelchair, bath, etc.
- I need to be fed but my meals must be mashed up with a fork and well moistened, but not like a liquid. I cannot cope with hard lumps such as piecrust or tough meat and will stop eating if I cannot clear my mouth. Sometimes I will stop eating for no reason at all and become awkward, this is when you need to be patient and just continue. I will then carry on eating, but in my own time.
- I need you to encourage me to hold my drinking bottle.
- Because I have a severe bite reflex it is very important that I use my soft spoon and my own drinking bottle (it's just a baby's bottle, but that's all I can manage). The spoon I use is a flexible type. I always carry an appropriate spoon and bottle in my travel bag whenever I go out.
- I rarely have epileptic seizures now, but if I do I may sleep afterwards for a short period.
- I sometimes have to be given Oral Midazolam if my seizures haven't stopped after 5 minutes, 2ml only DO NOT GIVE A SECOND DOSE WITHIN 8 HOURS.

I need support when laying on my mat or the floor.

- When I am lying on the floor or using my mat I must have my legs supported, I use a special wedge, but a pillow will do the same job if my wedge is not available to you. Please remember that I must not be wearing my shoes when laying on the mat/floor.
- Position the wedge/pillow under my knees; this will prevent excess pressure on my feet, as I cannot straighten my legs.
- I also use two smaller wedges, which are positioned each side of my hips, smaller pillows are just as good or a rolled up towel each side will do the same job, this prevents me from rolling over.
- It is very inadvisable to leave me alone when I'm on the mat/floor, as I may start poking & scratching my Vesicostomy and Gastrostomy, and it would cause infections and soreness, I then become ill, this in turn means visits to the Doctor's or even the Hospital.

I need to be positioned in my bed correctly.

- When I am put to bed I must be lying in the correct position, I have special wedges for this, which need to be positioned in the correct places, see photos at the end of this Plan.

## What I do and what I mean

What is happening	➡	What I do	➡	What I mean	➡	What you should do
		I make kissing noises		I am pleased about something or I am enjoying something or I want a kiss		Play along with me
		I hold my breath then snort down my nose		I'm annoyed as have been stopped from doing something e.g. poking eyes, biting fingers, etc		Continue stopping me, put a toy in my hand as this will give me something else to occupy my hands
		I lower my head when been fed		Refusing to be fed, I'm being awkward		Be patient, lift my head and continue to feed me
		I say Diddid I say Mummum I say Babba I say Ahaa		Dad, Daddy Mum, Mummy Baby I'm being clever		Answer back, reply, acknowledge me
		I lean sideways over the arm of my wheelchair		I'm uncomfortable in my chair		Reposition me
		I will shout and bang toys on my table		I am happy and having fun		Continue playing along with me
		I tap my left hand under my chin		I want you to tap me under my chin so I can make		Tap gently

What is happening	➡	What I do	➡	What I mean	➡	What you should do
				Indian sounds with my mouth		
I'm about to be naughty		Give you a sly look		Checking to see if you are looking at me before I attempt to poke eyes, ears or bite finger's		Keep an eye on me because I'm about to do something I shouldn't do
I'm breathless (Sometimes I become very breathless due to my Scoliosis)		Struggle to breath				Stop what you are doing and please place me in the recovery position, I may need O2 to help me.
I'm having a seizure		My eye's become fixed, I have a ruckly cough, I turn pale, I sometimes go rigid and may bite my tongue		I'm going to have or I am having a seizure		Talk to me, stroke my face to try and bring me around, if this fails after 5mins administer 2ml syringe of Midazolam in my mouth.
It's getting late and I'm falling to sleep in my chair		I get heavy eyes and my head drops		I want to go to bed		Take me to bed, but only if 2 hrs or more have elapsed since my last feed
		Push my bibs / clothes / fingers in my mouth. Bend my fingers back		I am being naughty and testing you.		Stop me. Put a toy in my hand.

## This is what my support workers think is working and not working

What works, makes sense, the up side:

- He is given healthy and nutritious food.
- He is assisted with exercise.
- He goes out and about with his family regularly.
- He enjoys his home and enjoys routine, such as playtime, massage time.

What doesn't work, doesn't make sense, the down side:

- He needs a team of support workers that he is comfortable with. Having new staff is often a problem for him.
- He needs to be encouraged to drink more juices. Attention is always needed in this area.
- It can difficult to understand what he is trying to communicate.
- Obtaining the correct equipment for his everyday needs as it is causing further damage to his health and wellbeing.
- Cannot go swimming as the water is too cold at public swimming baths, and he really enjoyed the swimming at his previous school.

## What my family thinks is working and not working

### What works, makes sense, the up side”

- His support workers make considerable efforts to know and understand him as a person.
- His adapted vehicle and chair make outings easy and safer.
- Going out in the community on a regular basis.

### What doesn't work, doesn't make sense, the down side:

- Ongoing problems of obtaining specialist equipment, which is putting his health at risk.
- Routines are not always being followed.
- Health & Safety issues related to swimming override his individual health and leisure needs.
- We don't feel we are equal partners in his care.
- There is a need to find more leisure activities to replace those now 'lost'.
- He still has no physiotherapist and Occupational Therapist from health. Throughout his childhood he had regular contact, as soon as he left school everything just stopped which has greatly affected his health and wellbeing.

## What you need to be to look after me

Apart from my Mum and Dad I have always had to have help from other people to support me. The people that support me have to be very special and have some very special qualities. They need to be:

- Sensitive and intuitive
- Someone who has a real sense of humour
- Patient and understanding, able to work at my pace and willing to get to know and like me
- Someone who can see beyond my physical care needs
- An observant person who can watch, listen and learn
- Someone who is confident and ready to adapt to my needs
- An imaginative person who is not afraid to try different ways of supporting me
- Someone who has high standards in all things
- A person who will 'go the extra mile' and show commitment
- Someone who respects my home and lifestyle
- A person who is organised and can follow systems and routines
- Someone with initiative who can plan ahead
- Someone who is able to respond to my verbal and non-verbal communication
- A person who will get to know my likes and dislikes and allow these to lead my daily life and activities
- Someone who will put my needs and wishes before their own
- Someone who is prepared to evaluate their approach to me and change if necessary



## What we have decided to do

### Actions from what is Not Working:

- Family says: Health & Safety issues related to swimming, override his individual health and leisure needs.
  - Action: Being looked at by parents (nothing available local)
  
- Family says: He needs to be encouraged to drink and eat. Attention is always needed in this area.
  - Action – Everybody involved in feeding him to contribute to this issue.
  
- Family says: It is sometimes difficult to understand what he is trying to communicate.
  - Action – All people involved with him to contribute to the communications section in this Person Centred Plan
  
- Family says: Routines are not always being followed.
  - Action - Everybody to contribute to the preparation of a new Personal Support Plan. Parents to ask all people involved with him to contribute.
  
- Family says: There is a need to find more leisure activities.
  - Action – Family to investigate new leisure interests and activities, in both the home and community.

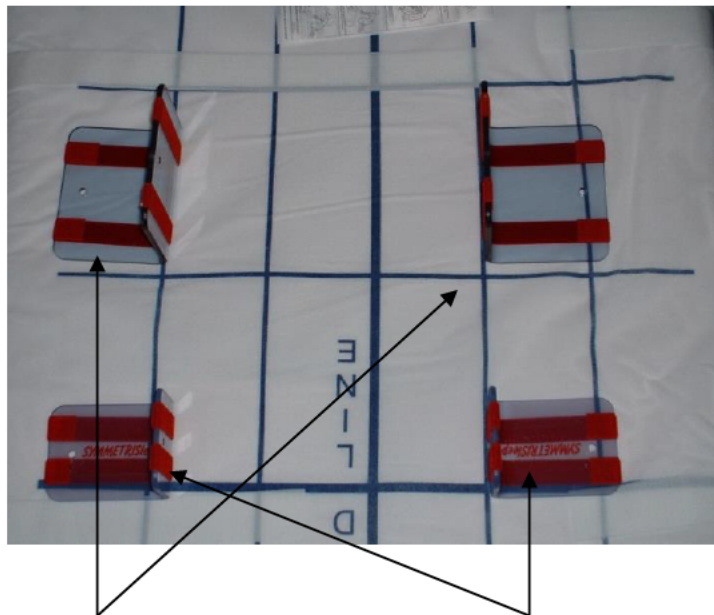
## Key Guides

*Incontinence Pads*

INSERT PHOTO HERE

Photo for illustration only as design may change

*Sleep Systems*  
*Stage One*



Two large supports for upper body	Two small supports for lower body
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This is the approximate positions of the supports but will need some alterations when all other covers are in place and NAME is on the bed.

INSERT PHOTO HERE

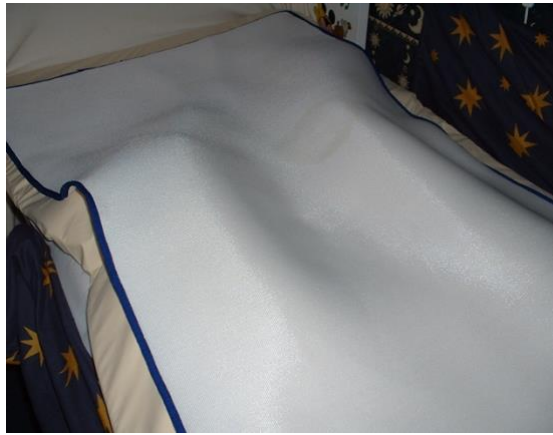
Large supports positioned 4-5 inches below arm-pit	Small supports positioned against hips, for support
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This is the approximate positions of the supports but will need some alterations when all other covers are in place and NAME is on the bed.

### *Stage Two and Stage Three*



Place padded mattress over supports, covering the bed.



Next, air sheet to be placed over padded mattress.

### *Stage Four and Stage Five*



Next, place stretch sheet over and tuck in under bed mattress.



Next, place leg support onto bed.

### Stage Six and Stage Seven



Next, supports may need to be repositioned when **NAME** is placed onto the bed. Repeat for other side.



Next, place leg supports under his knees, keeping **NAME** as straight as possible.

### Stage Eight

**INSERT PHOTO HERE**

Hands to be left outside the covers at all times, cover's to be securely tucked in on both sides of the bed.

HANDS NEVER TO BE UNDER THE COVERS

INSERT PHOTO HERE

Lap Strap	Harness	Tray location points
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The Wheelchair is for outdoor use only (colour may vary)

DO NOT ALTER ANY FASTENINGS ON MY CHAIR

Ensure harness straps are used at all times.

Tray is secured to each arm of chair, so I can play with toys, always in position whilst I'm in my chair.

Tray to be used at all times.

INSERT PHOTO HERE

Tray fitted		Towel tucked as shown.
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A towel is tucked each side to stop me from getting my hands under my tray to poke my Vesicostomy and Gastrostomy.

Tray to be used at all times.



Shoes to be worn when outdoors, ankle straps no longer needed or used.

Ensure harness straps are used at all times.

Tray is secured to each arm of chair, so I can play with toys, always in position whilst I'm in my chair. Towel used to stop me from getting my hands under the tray to poke my Vesicostomy.

Tray to be used at all times.

End of plan