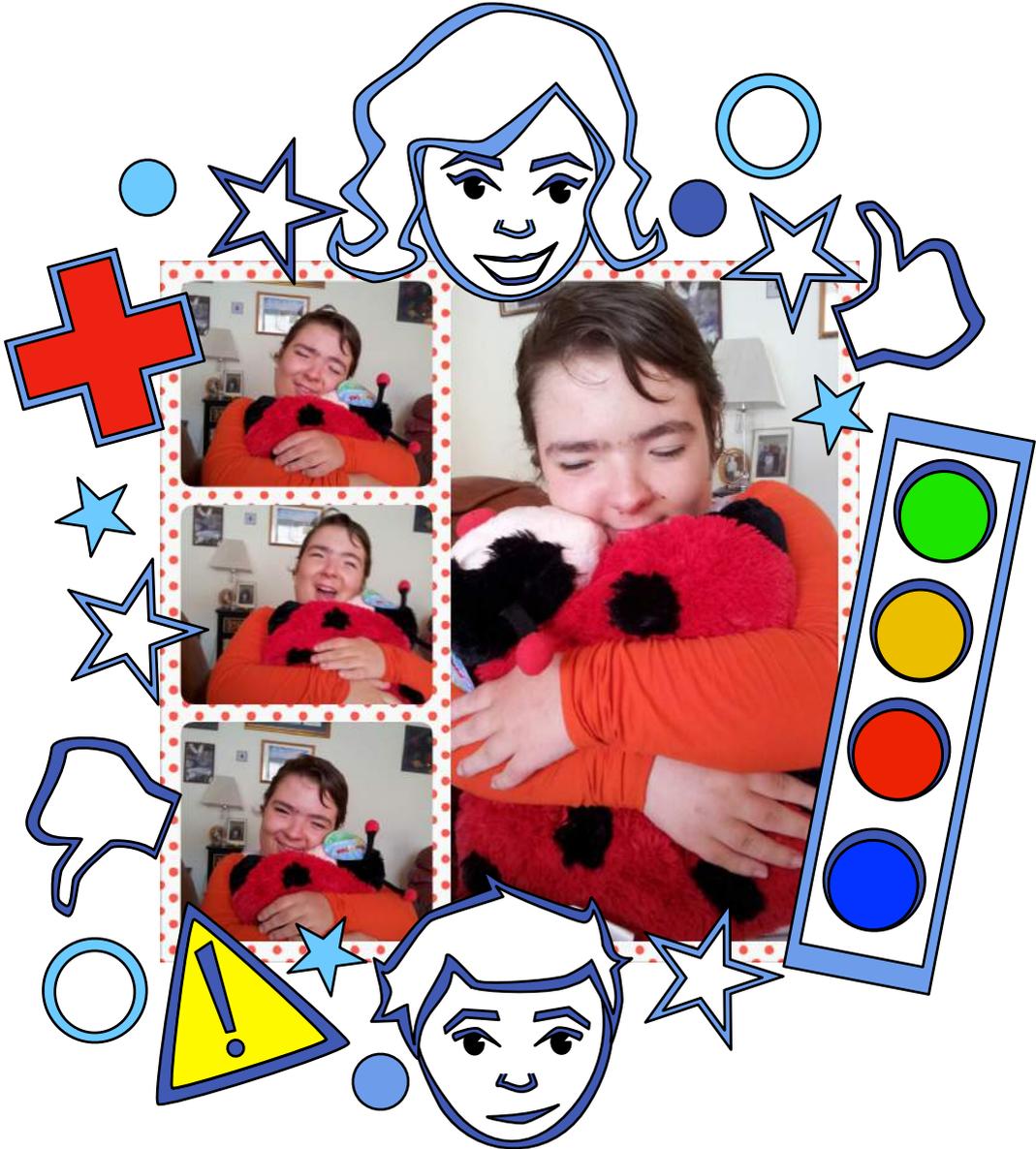


# Communication Passport

## Laura Sanger





Hi! My name is Laura,  
welcome to my  
communication passport.

Due to my complex  
communication disorder,  
I can't verbally tell you  
how I would like my life  
to be. But if you take the  
time to read my  
passport, you will find  
out about all the things  
that make me who I am.

# Contents

- Emergency Information
- Current Medication
- My Diagnosis
- How I Communicate
- Keeping Me Safe
- My Sensory Profile
- Things I Like
- Things I Don't Like
- My Behaviour Support Plan
- Diet & Eating Habits
- Personal Care & Hygiene
- My Family
- Thank You



# Emergency Contact Information

**Mother**

Kate Sanger

**Home:**

[REDACTED]

**Mobile:**

[REDACTED]

**Sister**

Jenny Sanger

**Mobile:**

[REDACTED]

**Aunt**

Susy  
Robertson

**Home:**

[REDACTED]

**Mobile:**

[REDACTED]

**Doctor**

D. Kennedy

**Pitlochry  
Surgery:**

[REDACTED]

**Medications:**

Losec

Domperidone

Citalopram

Peptac liquid

Paracetamol (headaches)

Codiene phosphate  
(migraines)

**NO KNOWN  
ALLERGIES**



# Current Medication



Time	Medication	Administration
8am	Losec (20mg)	By spoon, dissolved in 4ml of water
	Domperidone (10ml)	By spoon
12pm	Domperidone (10ml)	By spoon
4pm	Citalopram (5 drops, measure carefully)	By spoon, mix with 3ml undiluted juice*
8pm	2 x Losec (20mg)	By spoon, dissolved in 8ml of water**
	Domperidone (10ml)	By spoon

**Notes:** Paracetamol (10ml) can be given for headaches or period pain. Peptac liquids (10ml) can be given for reflux or gastric pain.

**Times for medicines are guidelines & can be flexible to suit circumstances (e.g. bedtimes, mood, behaviour)**

Show me pictures of medicine bottles (overleaf) to help identify pain.

**\*Citalopram has a very bitter taste, have a drink handy for afterwards. \*\*Give tablets plenty of time to dissolve, & allow time to a drink juice in between spoonfuls.**

# My Diagnosis



I have a condition called Cornelia de Lange Syndrome (CdLS for short).

CdLS is a genetic disorder which means it is present at birth, but it is not always diagnosed at birth.

CdLS causes a range of physical, cognitive, & medical challenges for both genders equally.

**How does CdLS affect me? Check out the points below:**

**Cognitive skills** - CdLS causes me to have severe learning difficulties.

**Speech and language** - CdLS causes me to have complex communication disorder.

**Challenging & self-injurious behaviour** - I can lash out at others or myself if I am in pain or my needs are not being met.

**Medical** - I have gastric reflux, which causes me a lot of pain & nausea; I also have Raynauds, a hydronephrosis of my left kidney, hip displasia (both hips), hiatus hernia, & hirsutism.

**Mood change, anxiety, & autistic like behaviours are also a part of my condition.**

Other physical features caused by CdLS that you might notice are my small stature, my short upper arms, my large thick eyebrows that meet in the middle, my long eye lashes, a small sinus at the base of my spine, curved fifth fingers on both hands, crowding of the teeth (though mine are a lot better since I had some removed), & small hands and feet. I also have narrow ear canals & a high arched narrow palate.

# MEDICAL ALERT

The bearer of this card has  
**CORNELIA DE LANGE SYNDROME** a  
condition that may cause the following:

- A. Growth and Endocrine Problems
- B. Gastro-intestinal problems
- C. Seizures
- D. Cardiac problems
- E. Neurological, learning and  
behavioural problems
- F. Oro-dental problems

# CORNELIA DE LANGE SYNDROME



Cdls  
*care card*

## Personal Details

Name \_\_\_\_\_

DoB \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Phone \_\_\_\_\_

## Emergency Contact

Name \_\_\_\_\_

DoB \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Phone \_\_\_\_\_

## Further information

Further information on CdLS can be obtained from  
**the CdLS Foundation UK and Ireland**

**Tall Trees  
106 Lodge Lane  
Grays  
Essex RM16 2UL**

**Tel/Fax: 01375 376439**

**e-mail: [info@cdls.org.uk](mailto:info@cdls.org.uk)**

**Web: [www.cdls.org.uk](http://www.cdls.org.uk)**

The Foundation is the support group for carers and professionals involved in the life of the person with CdLS. The organisation is part of an international federation of CdLS groups and participates in the international Scientific Advisory Council (SAC) which features specialists from around the world with particular emphasis

# Health Professional Information for Cornelia de Lange Syndrome (CdLS) [Brachman-de Lange Syndrome]

CdLS is a rare, usually sporadic, dysmorphic syndrome with a birth incidence of between 1 in 40,000 and 1 in 100,000. The diagnosis is clinical and usually based on the combination of distinctive facial appearance, limb anomalies and prenatal onset short stature. Misdiagnoses are not uncommon and this care card assumes that a firm diagnosis of CdLS has been made by an experienced dysmorphologist. The aim is to highlight treatable complications of the disorder and to provide a record for health professionals of all clinicians involved with each patient.

## *Growth and Endocrine Problems:*

Almost all children with CdLS show both pre and postnatal growth failure in spite of adequate diet. The use of specific CdLS growth charts is strongly recommended and these are available at no cost on-line at <http://www.cdls.org.uk/background>. Therapy with recombinant growth hormone is generally considered non-beneficial. Cryptorchidism and micropenis are relatively common in males. Puberty can be slightly delayed in both sexes but may be incomplete. Primary amenorrhoea is common.

## *Gastrointestinal Problems:*

Gastro-oesophageal reflux disease (GORD) is very common and under-recognised. Undiagnosed GORD may be an explanation for behavioural abnormalities, pain, self abuse recurrent respiratory disease or other puzzling symptoms and signs. Many children benefit from endoscopy and/or a therapeutic trial of medication such as a proton pump inhibitor. Fundoplication may be required. Barrett's oesophagus and Sandifer complex can occur. A low threshold for referral to a paediatric GI specialist is recommended. Acute surgical presentation may be due to caecal volvulus and malrotation with nonfixation of the caecum and ascending colon. Diaphragmatic hernia, duodenal atresia and annular pancreas are also non-randomly associated with CdLS.

## *Neurological, Learning and Behavioral Problems:*

Learning disability of variable severity is almost universal. Skills charts are available at no cost on-line at <http://www.cdls.org.uk/background>. Expressive language delay is particularly common and early use of signing is recommended. Hypertonicity and hyperreflexia are common. There may be signs of an autonomic neuropathy. Some children have specific behavioural problems including autistic-like features and self injury.

Unusual hand posturing at eye level is very common. Seizures may be under-recognised and non-convulsive seizure activity has been observed.

## *Orthopaedic Problems:*

Bilateral upper and lower distal limb malformations are very common but highly variable, ranging from small hands with proximally placed thumbs to oligodactyly with severe hypoplasia of the forearms. Fixed flexion contractures of the elbow are common. Even with severe anomalies the manipulative abilities are often remarkably good. Hip dysplasia may be a significant and under-recognised problem in CdLS.

## *Oro-dental Problems:*

Cleft palate occurs in ~20% of cases although submucous clefting is probably under-recognised. Nasopharyngeal airways tend to be narrow. Micrognathia, microstomia and dental crowding are very commonly associated. Dental caries may be problematic and periodic examination and treatment under anaesthesia is often required.

## *Ophthalmology and Audiology:*

Ptosis, recurrent blepharoconjunctivitis and myopia are common in CdLS. Ptosis surgery may assist in motor development. Baby shampoo eyelash scrubs may be helpful in relieving recurrent red eye discharge although some children may require nasolacrimal duct probing for obstruction. Nystagmus, mild microcornea, and/or strabismus can occur. Cataract and glaucoma have been rarely reported and may represent chance occurrences or the result of self-injury. Children with severe myopia may be at higher risk for retinal detachment. Optic nerve pallor is uncommon although a visually insignificant pigmented ring around the optic nerve is almost universal. Hearing loss is very common and assessment by a paediatric audiologist is recommended. External auditory canal stenosis is very common.

## *Cardiac Problems:*

Congenital heart disease has been reported in 20% of cases, usually ventricular septal defects or pulmonary artery stenosis. Perioral blueness is very common and may not, in itself, require further investigation.

## *Dermatology:*

Cutis marmorata and generalised hirsutism are very common features of CdLS and do not merit further investigation.





# Communication

I have a complex communication disorder. This means that in order to communicate with me, there are some things you will need to know first.

## ***Please do:***

Give me plenty of time to formulate my thoughts & to respond to you

### **Provide me with open choice**

Aid my understanding through visual supports, gestures, repetition, etc.

### **Use short & simple language**

Break instruction down into manageable chunks of information

**Be patient. If I experience dysfluency (stuggling to get my sentences out), do not rush me.**

Check that I have understood what you have said or what I have to do.



Examples of things that help me communicate: cause & effect (e.g. switches); music & art; narrative (sensory stories, social stories), body language, gestures, objects of reference, photos.

# Communication

I have a complex communication disorder. This means that in order to communicate with me, there are some things you will need to know first.

## ***Please don't:***

Ask me more than one question at a time

**Ask me closed questions or alternatives (I tend to choose the last thing that I hear)**

Use lengthy, complex language

**Give me more than one instruction at a time**

Assume that I have understood something just because I appear to use a lot of language



# Communication

My vocabulary will amaze & amuse you. I am a great mimic & will repeat stories adding a little more fiction along the way.

**My understanding is not on the same level as my vocabulary & this can be misleading for people who don't know me.**

Here are some tips to help you communicate with me.



## ***When asking me a question:***

- *Look at my face*
- *Keep the question short & simple*
- *Give me time to answer*

## ***If I have to choose more than one thing (e.g. apple, crisps, or chocolate):***

I usually pick the last word I have heard. So mix the options around & repeat the question. This will give you a better idea of what I want.

## ***Use pictures or symbols to help, or chatbox.***

I love pictures, photos, & symbols, so I will take time to look at them (of course this depends on my mood). Also, I love to tell stories using my chatbox. The objects in there can help prompt my memories of what I have been doing. For example, if I've been to the shop a carrier bag will help me remember.

# Verbal Communication

**Sometimes what I say, is not what I mean.**

Here are some examples of my common expressions.

What I say:

What I mean:

"I have a feeling."

"I don't feel very well."

"What would you like?"

"I would like something, please ask me what I would like."

"And then?"

"What are we doing next?"

"Something wrong."

"Something is bothering me but I don't know how to tell you what it is."

"My bed is broken."

"Could you make my bed, please?"

"Excuse me, can I talk to you?"

"I want to talk to you, please look at me & listen."

"Uh oh, what's she done?"

"I have done something that I shouldn't have, you better find out quickly!"

# Verbal Communication

## **Sometimes I can be very quiet.**

Sometimes I don't feel like talking & will stare into space, & will not respond to any of your questions.

Don't worry though, this is just part of who I am. I will talk in my own time.

When you want me to do something, try not to overload me with information. Use a soft voice, even if I am being difficult. I respond better to a calm approach.

I am easily distracted, so if someone new comes into the room I might stare at them & ignore everything else.

**Sometimes I will stutter or repeat words. I can get anxious when trying to tell you what is on my mind, please be patient.**



If I am hand flapping or grimmacing, try placing a hand on my shoulder gently to reassure me you're still listening.

# Keeping me safe



**A  
L  
E  
R  
T  
  
W  
A  
R  
N  
I  
N  
G**

Keeping me safe can be a difficult job for my carer, as I have little awareness of danger.

**Never assume I will act appropriately to my environment. I need my carer to help me by supervising me. But please don't continuously invade my personal space.**



If you leave me unsupervised, I may try to open the door and take off (I am very quick!) I like to pace about & speak to everyone; keep me within your vision.

## **Taking me out:**

I can be very good or extremely difficult.

Always use my wheelchair when out doors.

I need two-to-one support or I need to be part of a larger group so that my carer has support should any problems occur.

Please don't cut corners - it can put me in the...

**Danger Zone**

# Sensory Profile

The following protocol must be adhered to at all times when working with Laura

I have been diagnosed with CdLS, which means that I can experience social anxiety & mood changes in certain social settings.

I have a history of challenging & aggressive behaviour; which I will display if unwell, anxious, or if my needs are not being met.

**I have hyper sensitivities & hypo reactivity.**

This means that I experience some sensations more intensely than the average person (hyper sensitivity) & that sometimes I fail to respond to things that are happening around me (hypo reactivity).

**I also have poor proprioception, postural motor difficulties, sensory discrimination difficulties, & visual spatial difficulties.**

Because of this, I will often use movement as a soothing mechanism. This means you might see me rocking, pacing, and generally unable to sit still. I might be doing this to help myself feel more aware of my body and where it is in relation to my environment. If I am doing this a lot, it can be a sign of increased anxiety.

# Sensory Profile

The following protocol must be adhered to at all times when working with Laura

My sensory profile means that tactile inputs and movement inputs are very important for me. I use repetitive touch (I usually have a squidgy toy that I carry around with me) to help me stay relaxed and calm.

I do this almost subconsciously, much like how a baby is soothed by sucking a dummy.

Sometimes I will put my toys down when I am engaged in activity, but if you watch me closely you will see that I am using my finger tips or touching the area around my mouth.

This is not necessarily a sign of anxiety or distress.

**I can feel 'overloaded' if there is too much expected of me.**



"Mr Tickle" is one of my favourite squidgy toys

A busy timetable that is too structured can be stressful for me, so please keep my timetable simple & flexible so that I can take part in & enjoy activities at my own pace.

# Sensory Profile

The following protocol must be adhered to at all times when working with Laura

**In addition to my sensory issues, I also have pica, which means that I might try to eat inedible objects.**

This can be very dangerous for me so I need my carer or support worker to be vigilant.

## What is pica?

Pica is characterised by the habit of eating objects which are not edible; for example, stones, coins, shampoo, & clothing.

Risks include: vomiting, constipation, infections, blockages in the gut & intestines, choking, & poisoning. Sometimes surgery is needed to remove objects from the gut or to repair damaged tissue.

I occasionally eat objects that are not meant to be eaten, but not all objects. At my developmental level, I like to put things in and around my mouth to explore or chew them. Occasionally I swallow them as a result.

For example, I often do this with threads on clothes, toys, and the rubber 'appendages' from my squidgy toys.

**If you see me putting something in my mouth or chewing something that may be dangerous, please distract me with an activity & discretely remove the unwanted object. If I realise that you are attempting to remove it, I may swallow or bite into the item.**

# Things I Like

(Mood & energy depending)

Carrying my handbag

Music

Carrying my squidgy toy

Music videos

Dressing up

Karaoke

Singing

Dancing

Foot spa

Hand massage

Sensory stories

People watching

Exercises (but not trampolining)



# Things I Don't Like

**I often experience social anxiety, low moods, & low energy levels.**

Please be mindful of this & do not put your expectations of what you think I might enjoy doing, above what I am capable of doing given how I am feeling.

**Forgetting this will likely lead to challenging behaviour - if I don't like my environment, I will act out so that I am removed from it.**

Things I don't like:

Big noisy crowded places

Too many choices (no more than 2 at a time, & if anxious, please make a decision for me)

Birds, feathers, spiders, & flies



Please be aware that I am very sensitive to your body language & tone of voice. If you are anxious, stressed or tired, I might pick up on it & also become anxious.

# Behaviour Support Plan

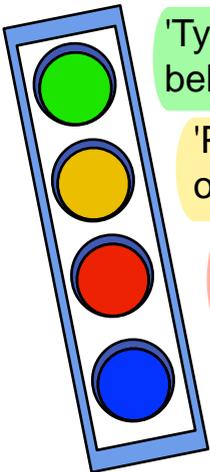
**My challenging behaviour usually has a function.**

I am letting you know that something is wrong: my needs are not being met, I am unhappy, or I am in pain.

To help my carers understand my communications through behaviour, they use a traffic signal analogy.

## Self-injurious behaviour:

- Throwing myself to the floor
- Biting the back of my hands
- Scratching my arms & hands
- Hitting my head with my hands
- Banging my head on the floor



'Typical behaviour' (Green)

'Problems are about to occur' (Amber)

'Challenging behaviour' (Red)

'Calming down - but remain cautious, could slip back to Red' (Blue)

**These signs can be subtle, please take the time to read on to find out how to recognise and react to them.**

## Behaviour causing risk to self, others, & property:

- Kicking
- Hitting
- Pushing
- Biting
- Throwing
- Swiping things off surface

# Behaviour Support Plan

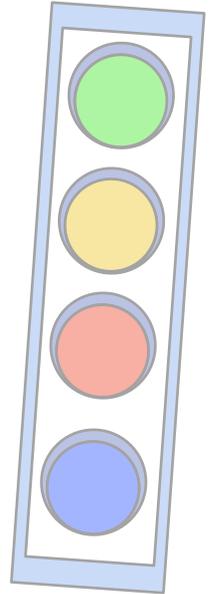
## Different types of strategy

### Proactive:

Strategies used to meet my needs without my needing to resort to challenging

### Reactive:

Strategies used to manage challenging behaviour as safely & quickly as possible.



## **Reactive strategies are not a time to teach new skills.**

The following pages will describe proactive & reactive strategies for each traffic light phase, as well as a description of the defining behaviours.



### **Please remember:**

Physical intervention should always be the last resort.

If there is any use of physical intervention, a meeting will be arranged to discuss how I ended up in this situation.

# Behaviour Support Plan

## Setting Events

Lots of people ask about the triggers for my behaviour, but it's important to know that **setting events** happen before triggers.

**A setting event is anything that increases a person's level of anxiety or unease, making everything else a bit harder to cope with.**

They can be **inside** events (pain, fear, anxiety) or **outside** events (noise, people, change).

They might have happened recently: e.g. a bad experience such as a hospital trip, or not getting enough sleep last night.

Or they might be currently happening: e.g. the lights are too bright, the room is too noisy, I don't feel very well.

Setting events build up over time. As they accumulate, the more likely I will display challenging behaviour in response to triggers.

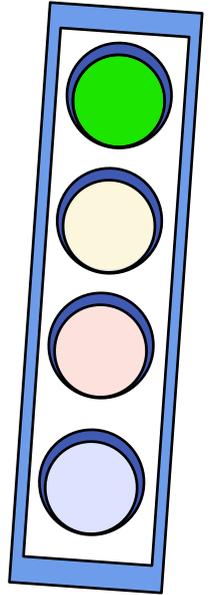
**Because of this, never assume that because I've enjoyed an activity one day, I'll be happy to do it the next.**



# Proactive Plan - Green Phase

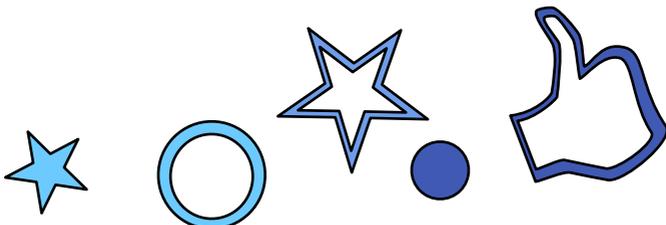
## Behaviours:

- ✓ Happy mood - lots of smiles, very chatty, relaxed
- ✓ Able to mix with others & enjoy activities with my peer group
- ✓ Happy to talk & communicate with peers
- ✓ More likely to comply with requests; e.g. Personal Care (PC) routines
- ✓ Easier for me to learn new skills



## Positive Support Strategies

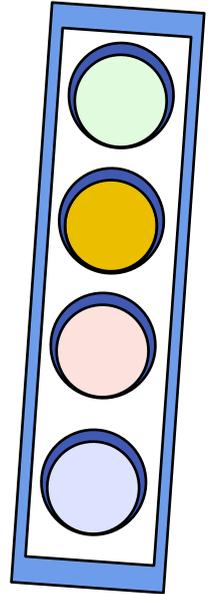
- ✓ Keep activities at a minimum; no more than 2 activities a day
- ✓ Make sure I am in good health & free from pain (I often get a sore head & sore tummy)
- ✓ Avoid saying 'no'; use 'later' or 'in a minute' instead
- ✓ Give me praise when I am doing well
- ✓ Allow me plenty of time to process information, especially during transition/times of change
- ✓ Make sure everyone working with me has read my Communication Passport!



# Active Plan - Amber Phase

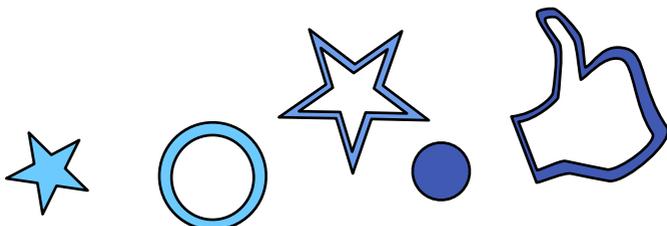
## Behaviours:

- Anxious mood - frown expression
- Constantly opening & closing my bag
- Talking to myself in a low, menacing voice; using bad language
- Shouting out & repeating conversations (more than usual)
- Grabbing your arm, pushing you away or dropping myself to the floor
- I get very emotional - crying then laughing



## Positive Support Strategies

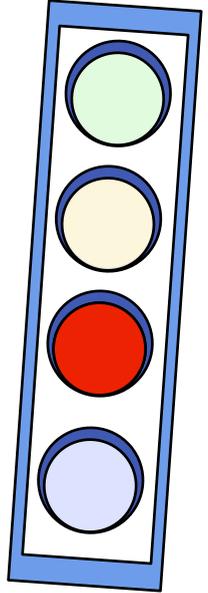
- ✓ Ask, 'What's wrong?'
- ✓ Distract me with a task I enjoy
- ✓ If outdoors, use wheelchair & get help/return to home or base
- ✓ Respond to my requests if possible
- ✓ Don't confront me or stand within striking distance
- ✓ Give me my space
- ✓ Offer me a drink
- ✓ Reduce any verbal commands or instructions



# Reactive Plan - Red Phase

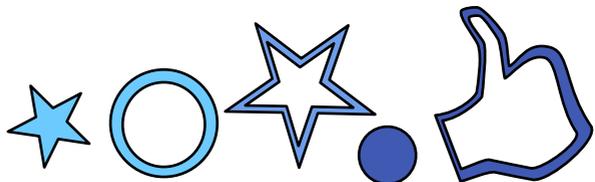
## Behaviours:

- Biting my own hand or yours
- Lying on the floor, or refusing to move
- Banging my head on the floor
- Hitting/grabbing/striking at anything or anyone within reach
- Throwing objects that are nearby
- May set off the fire alarm
- May put objects in my mouth



## Positive Support Strategies

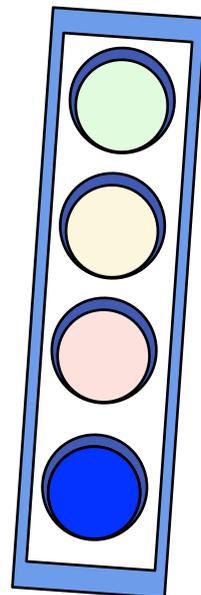
- ✓ Do not engage me in any conversation
- ✓ Reduce all demands/stimulation
- ✓ Place a hand gently on my shoulder, guide me to a chill out area
- ✓ In public, use a mobile phone to call for help
- ✓ Give me space, but keep me in sight
- ✓ If possible give me a change of staff member (works as a distraction)



# Post-Reactive Plan - Blue

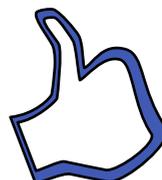
## Behaviours:

- More relaxed than Red (posture)
- Will seek time on my own, chat to myself over & over
- May ask for a cuddle
- May say sorry; but if my voice is menacing, I do not have control of my behaviour yet
- May take a drink & ask to join the group
- May lie quietly until I feel ready to leave chill out area



## Positive Support Strategies

- ✓ Allow me time in chill out area; this could be from 20 minutes to several hours
- ✓ Make no demands
- ✓ Show empathy
- ✓ Recognise the physical impact of the incident; e.g. offer me a drink (all that shouting is thirsty work!)
- ✓ Arrange a meeting with all those concerned so that we can learn from the incident - I don't like being in the Red phase, so I need help to make sure it doesn't happen when it is avoidable



# Challenging Behaviour

**My challenging behaviour usually has a function.**

Examples:

**Boredom**

If I am bored, I might rock myself back & forth to self-stimulate

**Frustration**

If I am trying to do a task that is too complicated or overwhelming for me, I may hit out because I cannot cope & wish to be removed from the situation

**I use my behaviour to get more control over my circumstances.**

When things are too noisy or too loud, I will get anxious & more likely to be disruptive.

Other examples:

- Communication/comprehension difficulties
- Change in routine/events
- Special events (hospital appointments, dentist, parties, etc.)
- Ill health or lack of sleep
- Choice - too little/too much

I will show signs prior to displaying challenging behaviour, some of the early signs are:

**Grimmacing**  
**Hand-flapping**  
**Rocking**  
**Loud voice/laughter**  
**Constant face-rubbing**  
**Menacing voice**

# Diet and Eating Habits

Keeping an eye on my diet is very important because I have gastric reflux & a hiatus hernia, which means that certain foods can cause me discomfort & pain.

## Food & drink that can cause me problems:

- High fat content foods
- Spicy foods
- Big portions of food
- Eating late at night
- Fizzy drinks

I love fizzy drinks! But they are not good for me. Sometimes, I am allowed a very small glass as a reward though. My favourites are coke & irn-bru.



I like to eat with my fingers, but do encourage me to use my special spoon. (Don't force me though, or else my food might end up on the floor...)



**Bread is hard for me to digest, so if you give me some, please make it a small portion.**

I love most food, including things that I shouldn't! Some of my favourite foods are:

- Chicken
- Ice cream
- Fish
- Tomato soup
- Salad

**Please encourage me to drink plenty.**

# Personal Care & Hygiene

**All pad changing & bathing must be done by a female & must be done in the privacy of my bedroom or the bathroom when in the house.**

If we are out of the house, please find a private room for me. This is important, please do this out of respect & to help me maintain my dignity.

When I have menstrual bleed please change my pad more frequently & offer me some paracetamol (10ml) as I often experience discomfort.



**Due to my hirsutism, I ask that my carer removes the hair from my chin area with a lady razor & soap or foam when I am in the bath.**

I have an electric toothbrush & prescribed toothpaste to help me preserve the enamel on my teeth. My acid reflux can cause accelerated erosion.

**No showers, please. I really don't like the shower.**

To wash my hair, let me lie back in the bath & pour water over my hair (careful of my eyes)

**I need help with all aspects of personal care & dressing.**

**I quite like having my hair brushed as a calm activity.**

Sometimes I can refuse to have my personal care addressed, but if you follow my behaviour support plan, I should remain relaxed & happy, allowing you to help.

# My Family



This is my Mum, Kate. I like to follow Mum around.



This is James, Mum's partner. I like it when we go out for lunch in Perth.



This is Sean, my brother. Sometimes we go to Glasgow & stay at his.



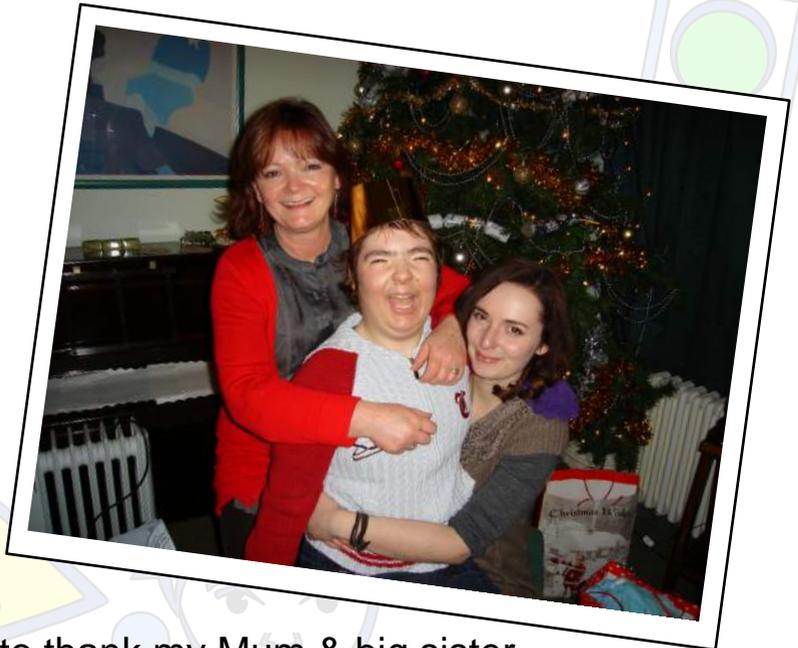
This is Jenny, my sister. She looks after me when Mum is away.





Thank you for taking the time to get to know me & how I communicate! I hope the preceding pages have helped you understand me a little bit better so that we can enjoy our times together.

Many thanks,  
Laura  
x x x



I'd also like to thank my Mum & big sister Jenny, for putting my communication passport together. I hope it helps everyone communicate with me as well as they do.