

CAN WE TALK?

**Getting in Touch with People with Severe Learning Disabilities who
have little or no Speech – and whose disability is linked to Autistic
Spectrum Disorder (ASD)**

**A Handbook for Families
and Carers**

**Phoebe Caldwell
Assisted by
Simon Willan**

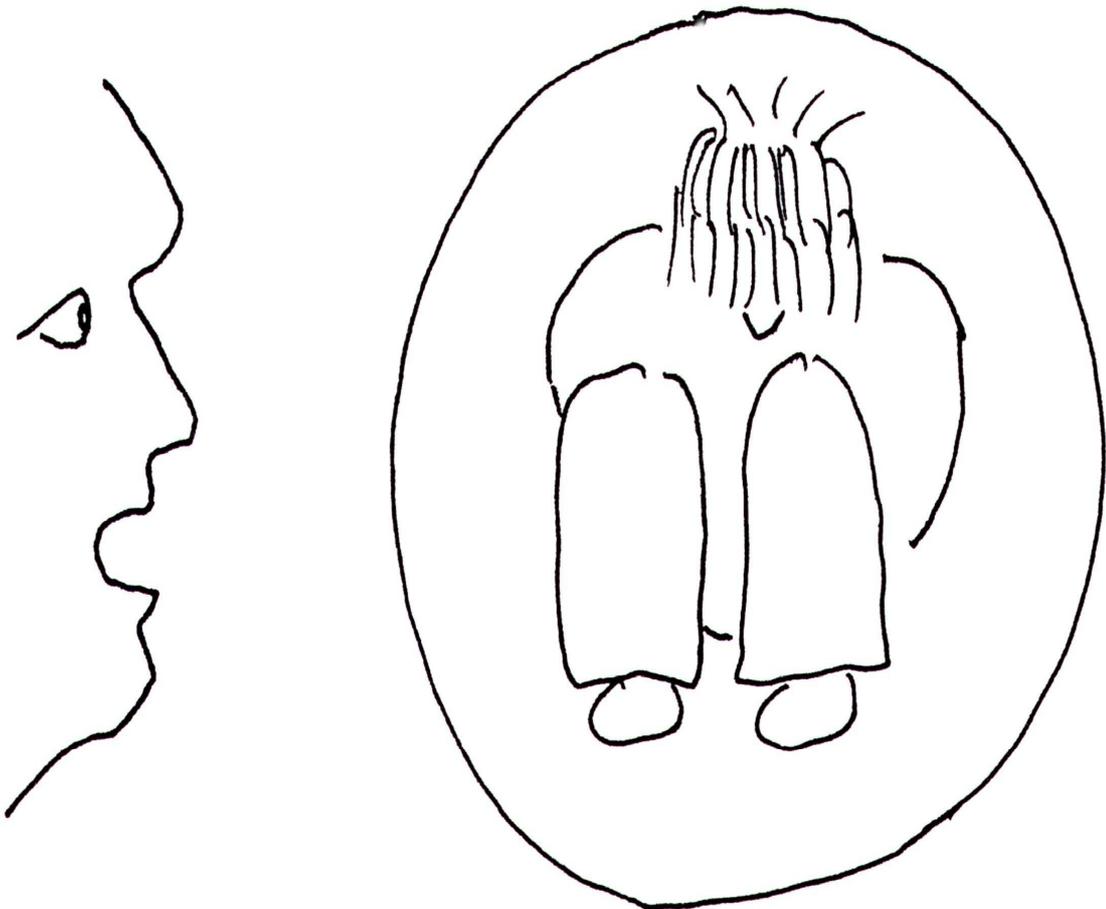
Phoebe Caldwell, Beechstones Barn, High Bentham, Lancaster LA2 7LA

Courtesy of North West Training Development Team (Partners in Policymaking)
www.nwtdt.com

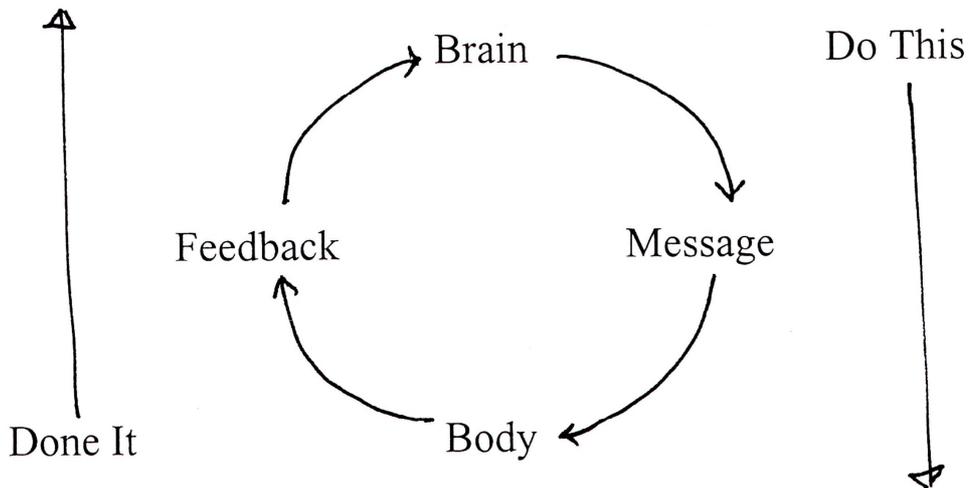
Can you talk to Mary?

Do you feel cut off from Janeed?

Some people with learning disabilities are difficult to reach. We cannot talk to them and they can't talk to us. They seem to be locked in a world of their own.

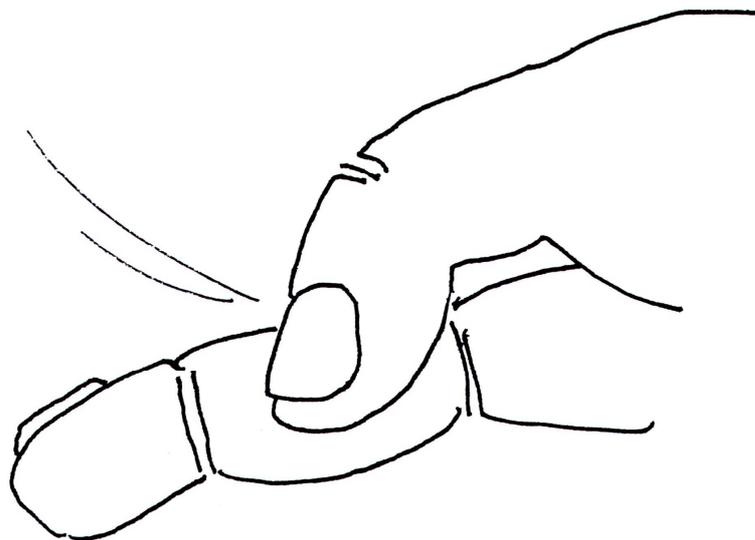


Instead of looking at and listening to the world outside themselves, they may be focusing on some activity or behaviour in a way which we call self-stimulating. It is part of a conversation going on between their brain and body. The brain sends a message to the body, 'Do this' and the body sends 'feedback' to the brain saying, 'Done it'.



For example:

The brain says, 'Scratch your finger with your thumb'. The thumb does this and sends back a feedback in the form of feeling to the brain, telling it that it has done so.



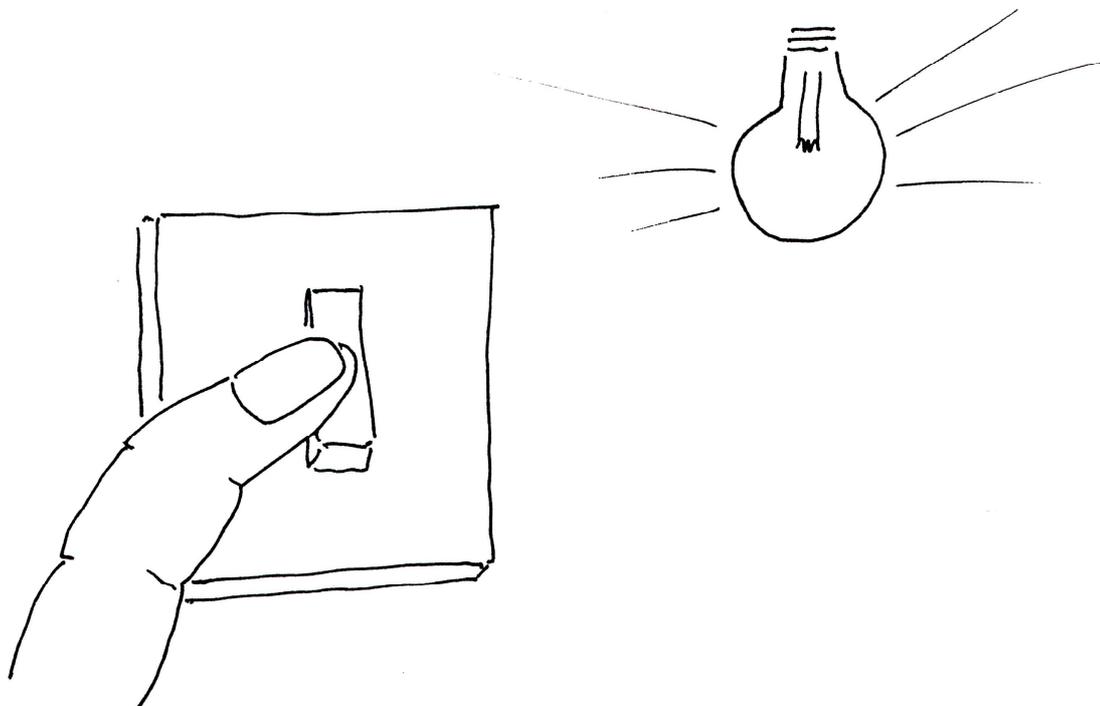
All their attention is focused on this activity. It feels safe, hard-wired in. In a world which they may see as chaotic and, in the case of ASD, perceive as painful, they know what they are doing. They are not listening to anything outside themselves.

They may be paying attention to physical feedback from their own bodies, for example, rubbing hands/fingers/thumbs, flapping hands, humming, making sounds, screaming, rocking, banging their heads, walking up and down. It may be some feeling, as little as just listening to their own breathing rhythm.

Or it may be that they are using some activity hijacked from the outside world to focus on. For example, they may be spinning objects, shutting doors, moving furniture, switching lights on and off or tearing paper.

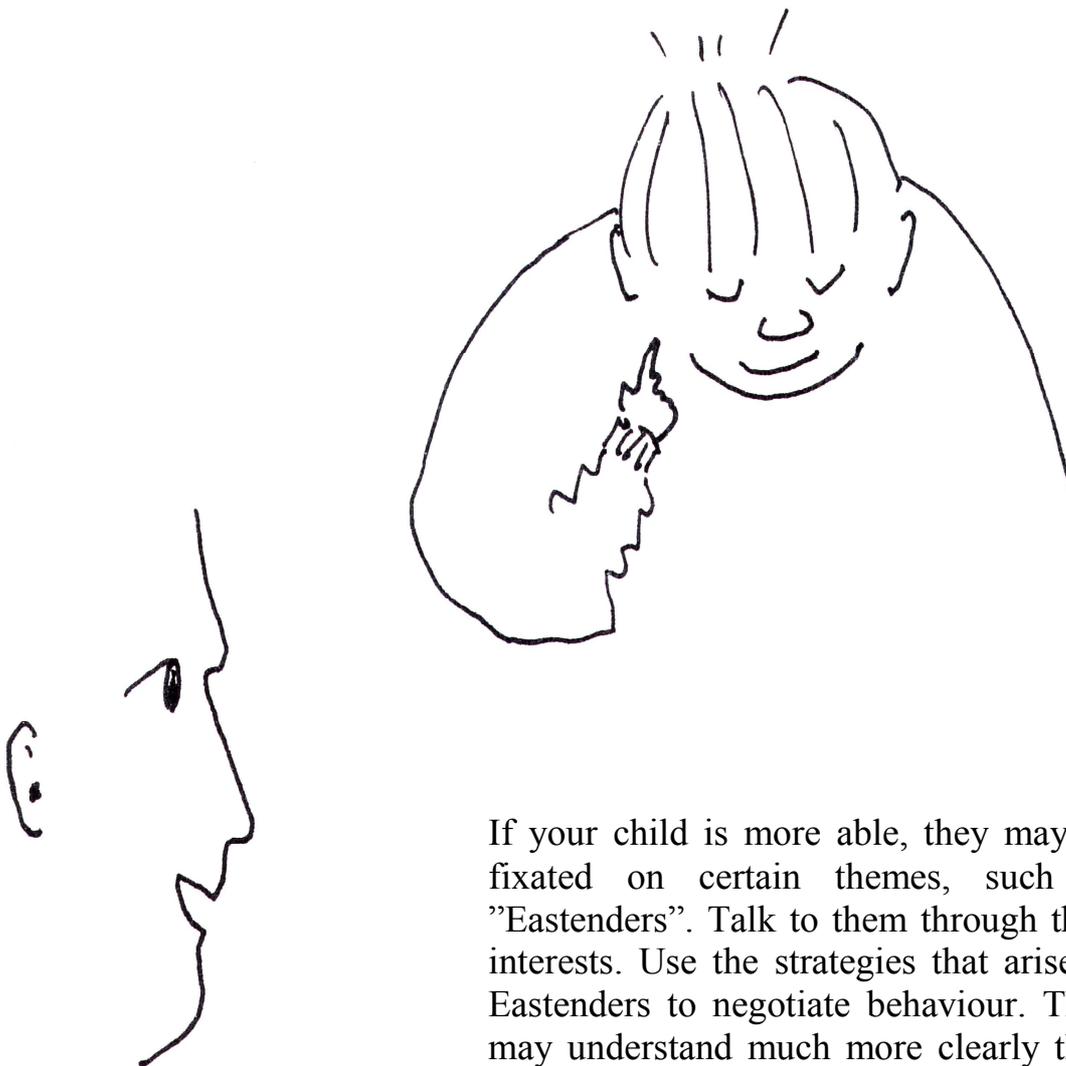
We need to learn to look at how a person is talking to themselves. What is the feedback they are giving themselves? What are they paying attention to? When they focus on themselves what is it that has meaning for their brain? What they are doing is using a language their brain recognises and feels safe with.

In order to get in touch with people we have to learn their language so we can speak to them in a way that their brains feel safe with. It's like a smart card with a personal code that we can use to get access to their inner world.



We have to learn to think in terms of body language.

First of all we have to look hard – and really listen to see and hear what they are doing (not what we think they ought to be doing but what they are doing.) Are they making any sounds or movements? These may be very small, as small as the sound of sucking their own saliva, or in the case of movements, difficult to spot since fingers may be rubbing themselves under crossed arms. However, once we know what we are looking for it becomes easier.



If your child is more able, they may be fixated on certain themes, such as "Eastenders". Talk to them through their interests. Use the strategies that arise in Eastenders to negotiate behaviour. They may understand much more clearly than trying to tell them directly.

What is Kevin doing?

Is he listening to his breathing rhythm,
tapping, making small sounds,
crying, screaming?

Is he stroking himself,
stroking something else, scratching himself,
pulling his hair, banging himself or the wall,
hitting himself?

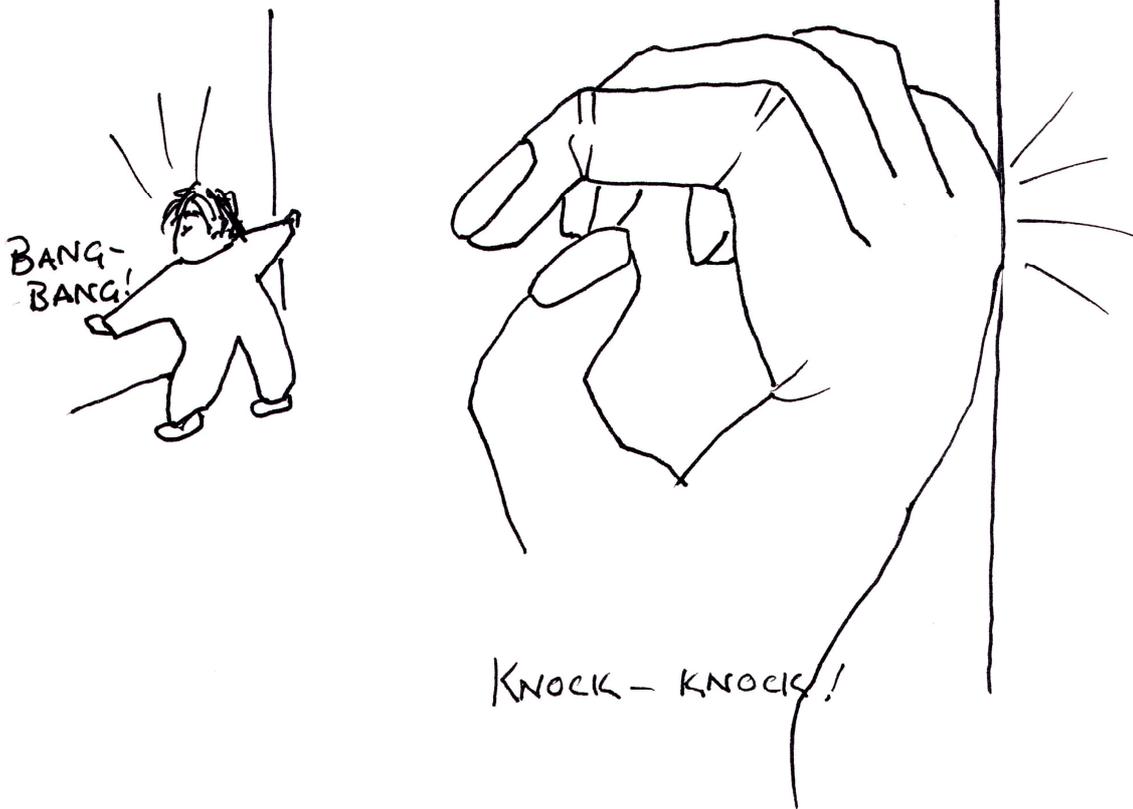
Rocking, swinging?

Poking his eyes, touching his face,
flapping fingers or objects,
spinning objects



If Kalil is banging himself or rocking, try banging the wall in the same rhythm? He will almost certainly stop in order to look and see what is happening. Wait a minute or two and then knock the wall again. If he repeats it, answer him.

You are trying to build up a conversation, taking turns as you would if you were speaking to each other.





Does Nick bite himself and scream?

“Arrghh”

Stand where he can see you, but not directly in front, put your arm in your mouth and echo his sound.



He may be so surprised that he stops, looks at you, and after a few more times, turns away and gets on with what he was doing before his outburst.

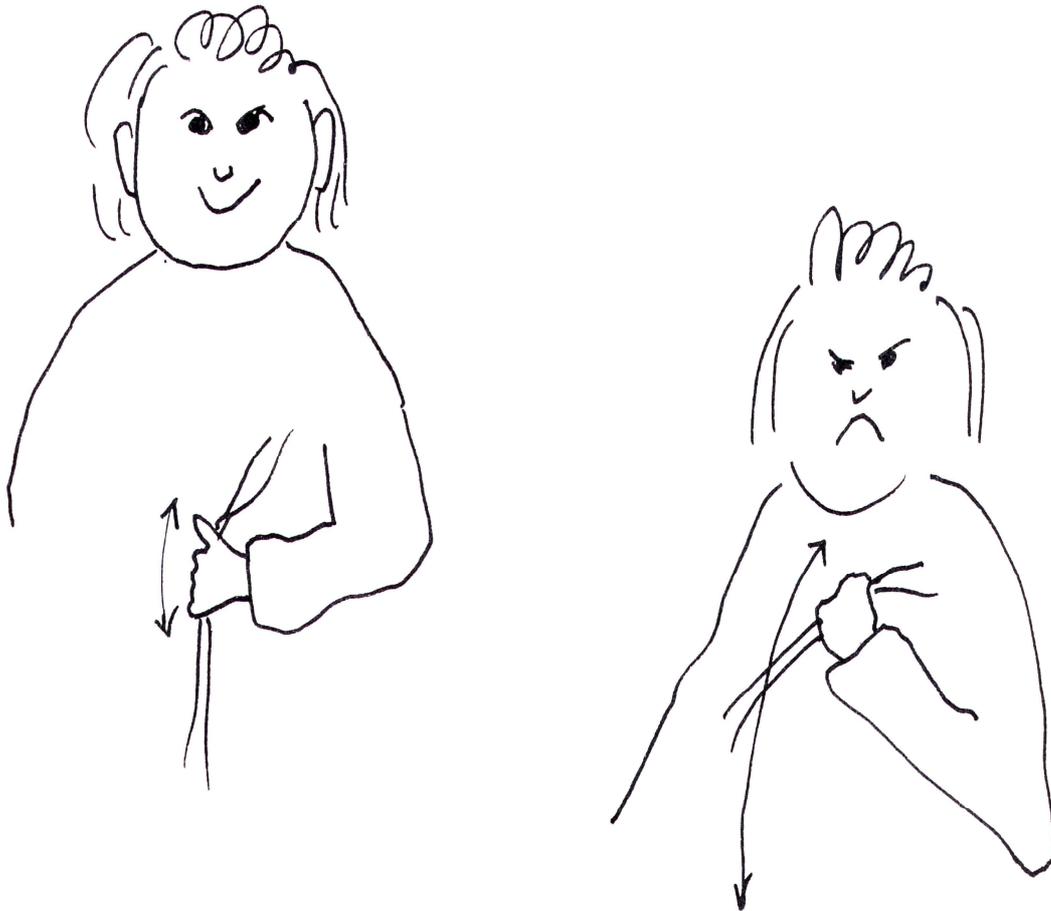
If he gets used to this, you may have to vary the rhythm of your sound.

“Arrgh-arrgh!”

Use a sound like “arrgh”, only softer to talk to him when he is not upset.

As well as seeing *what* they are doing, we need to think about *how* they are doing it. If they are upset, sounds may get louder, hands flap more agitatedly.

This tells us how they are feeling, if they are happy or upset.



Always Remember:

When a person is doing a Repetitive Behaviour, they know what they are doing.

It is a hard-wired, non threatening conversation with themselves.

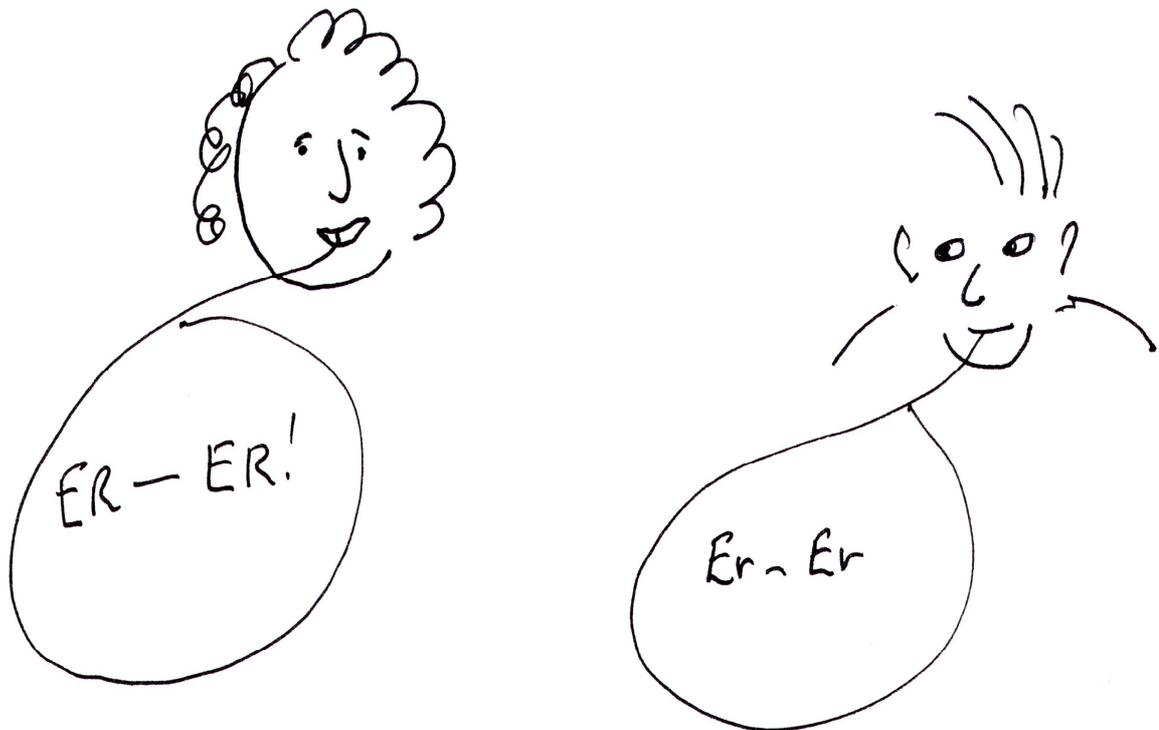
TRY JOINING IN!

Watch and see what happens.

Do they seem to stop what they are doing and listen? Are they interested, looking round to see where 'their sound', 'their movement' is coming from?

Try again. Watch and see.

You may have to do this several times until they realise that if they make a sound they get a response which means something to them, which they recognise.



Whatever the person is doing, answer them. In doing so, you will shift their attention from their inner world where they are listening to themselves, to the world outside where we can share our lives.

After a little while you will need to introduce some small variations. Watch carefully to see if they introduce new material and respond to this, otherwise they will think you are not listening to them and lose interest.

You may need to shift the mode in which you respond to them, answer them in a different but related way - but still using their rhythm. For example if someone is making a sound, you might make the 'shape' of the sound on their arm.



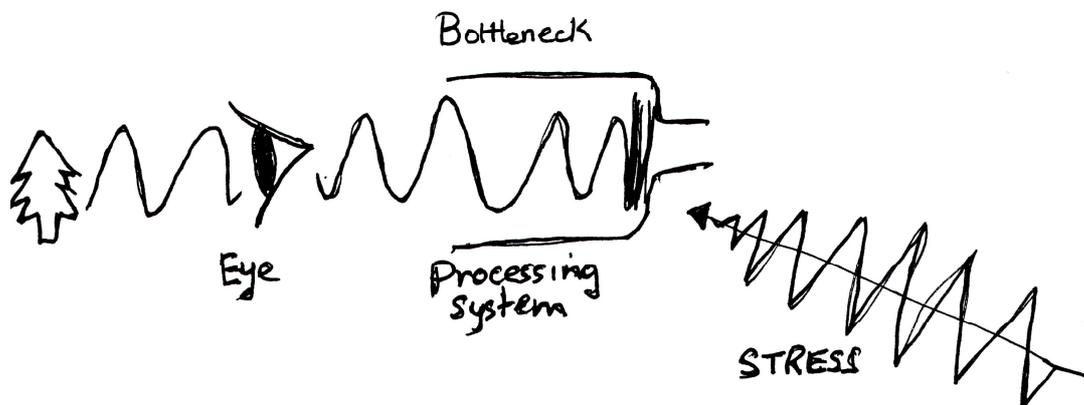
If someone is rocking you might change the direction of the rock from side to side to forwards and backwards, or while still rocking alter the rhythm by putting a small jerk in it. Make a game of it, but be prepared to introduce new material and follow when your partner offers it.

You can also use empathy by changing the quality of sound in your voice to respond to the emotional tone of their utterance.

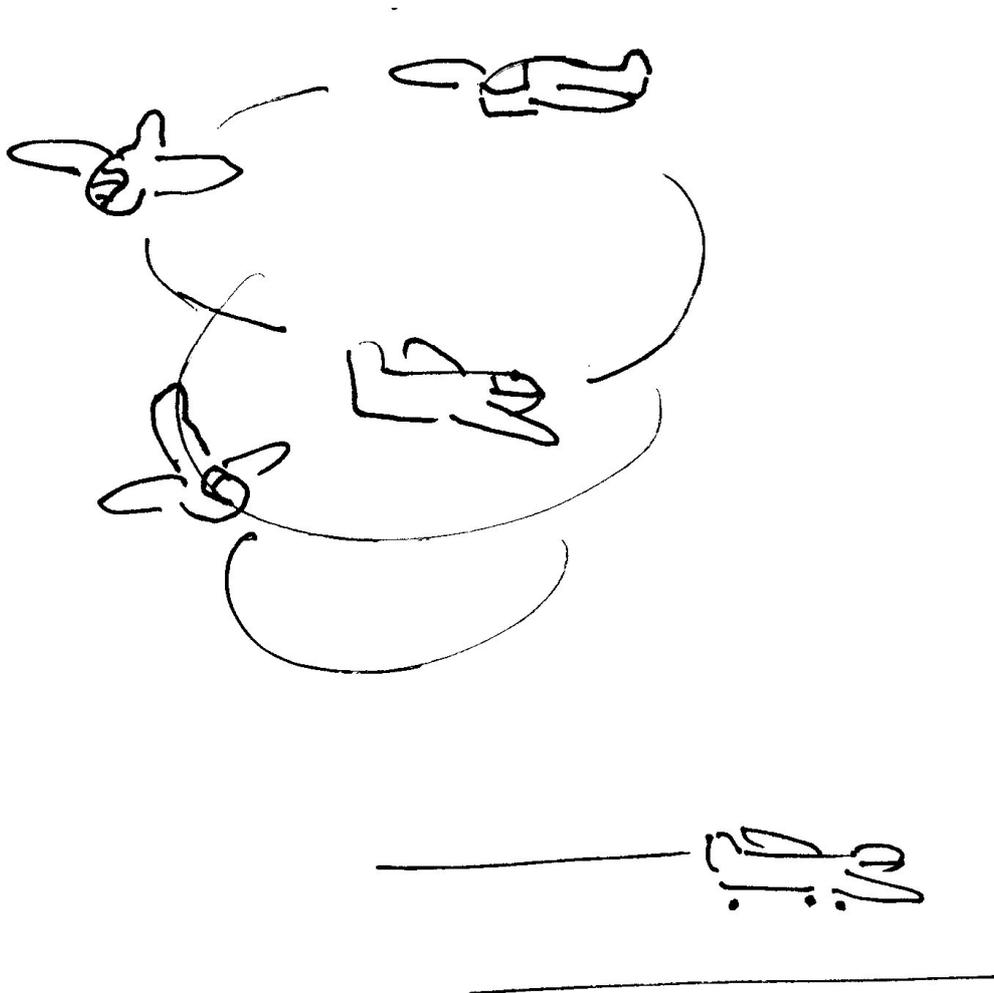
Some people cut themselves off because they have autism – autistic spectrum disorder – ASD. They find it difficult to make sense of what they feel, see, hear, smell and taste.



Sam can see, but on the way to the brain, the images hit a bottleneck and he cannot process them. Sam gets overloaded with images, sounds and feelings.



You can think of autism as being like a busy airport where more planes are coming than there is space to land the aeroplanes stack up.



If there are too many planes they might crash.

In the autistic brain unprocessed images, sounds and feelings also stack up, overload and interfere with each other.

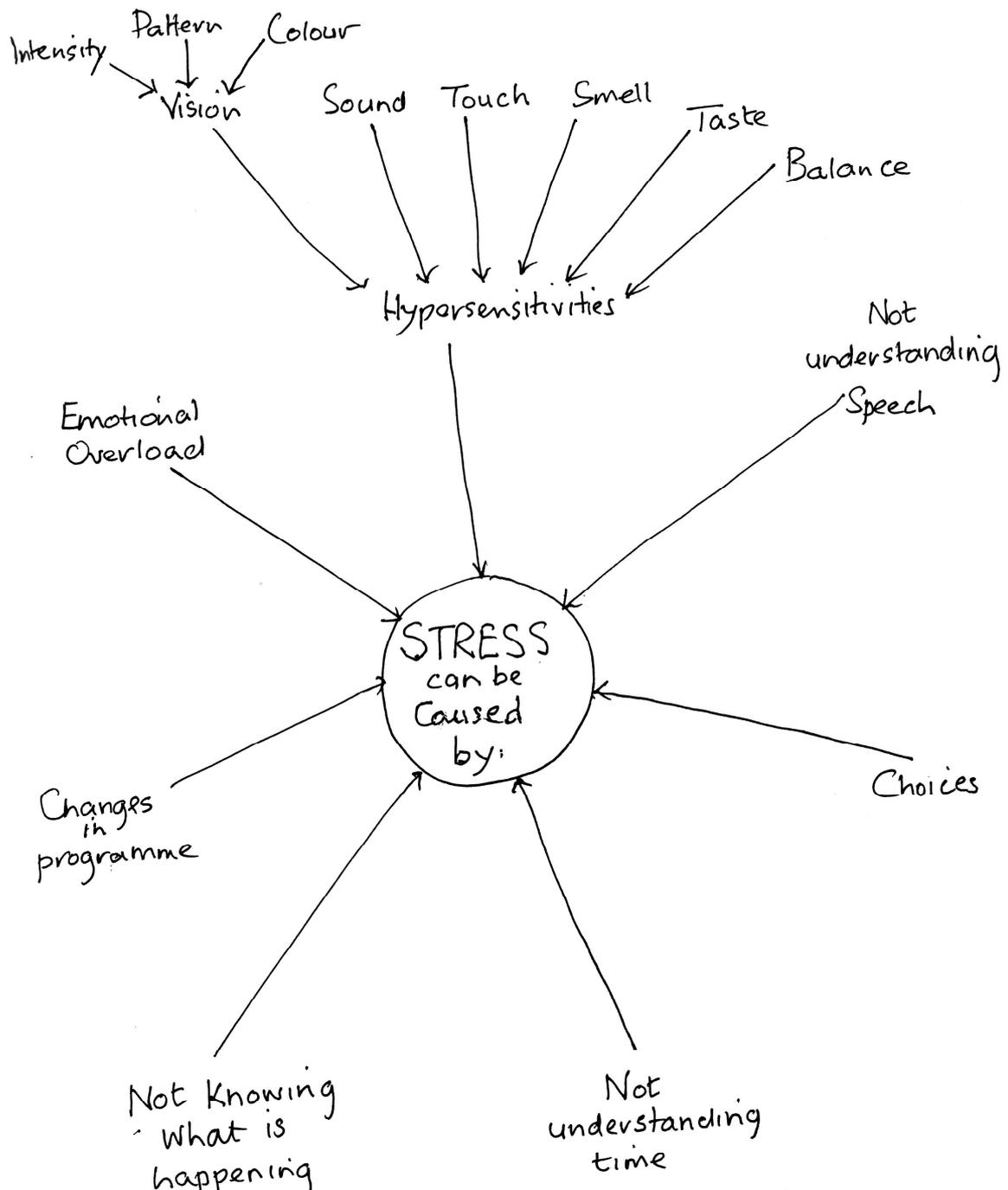
The more stressed Sam feels, the more overloaded he gets until the images, sounds or feelings break up into fragments and unregulated surges of feelings which are confusing - or maybe acutely painful.



It's like:

- “A cattle prod”
- “Being tuned into 40 TV sets at once”
- “Having a faulty volume control”
- “Being drowned in a tidal wave of feelings”
- “Living in a Kaleidoscope where the pattern never settles”
- “Having a lion in your head”
- “Agony”
- “Everything fires at once”

There are many different causes of stress in people with ASD. Not all will be upset by the same things. Some will find sounds difficult, others will find visual effects cause stress. One of the hardest things is people (emotional overload).



Vision

Look and see what it is that upsets Jenny.

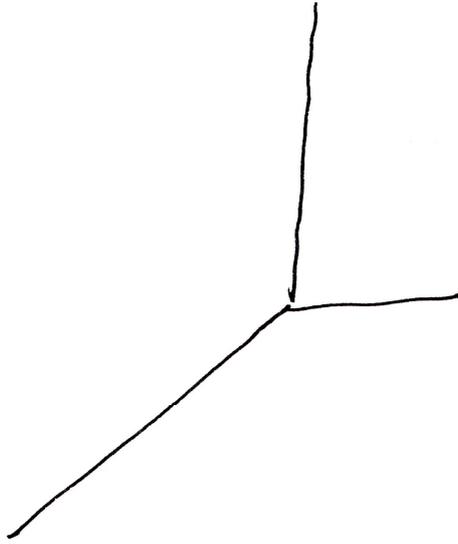
Does she screw up her eyes, avoid bright lights?

Use dimmer light. Avoid “jazzy” patterns in clothes (yours and hers) wall paper, carpets and pictures.

If she likes certain colours, use them.

CUT DOWN ON OVERSTIMULATION.





Lines we see as straight may wiggle for Herbie – like the line between the wall and the floor.

So

Herbie kicks the wall to know where it is.



(People with ASD may often touch objects, lick, or kick them to find out where they are).

Sounds

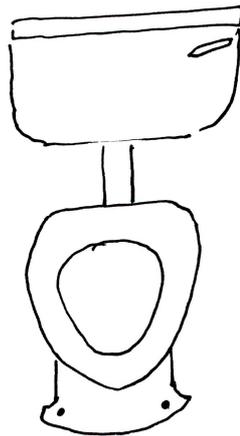


High frequency hums



small clicks

Loud noises



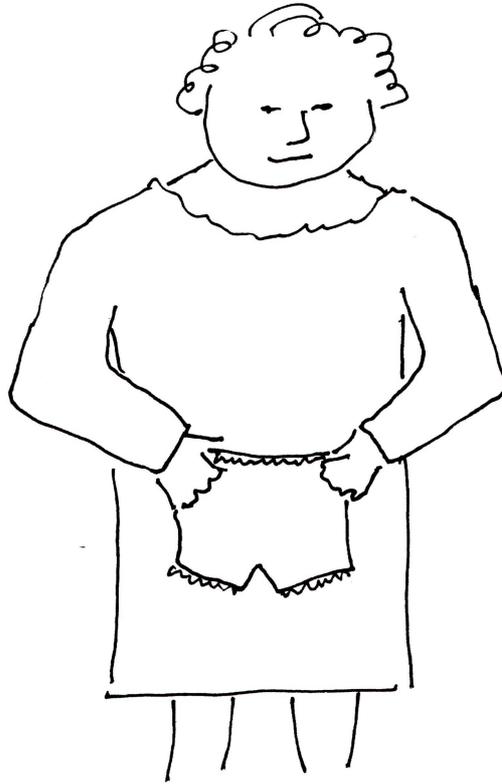
Telephone bells

These are some of the sounds that might upset people with ASD. Sometimes they are OK – Sometimes they.....



Touch

If you have to touch Sandra, ALWAYS show her what you are going to do first.

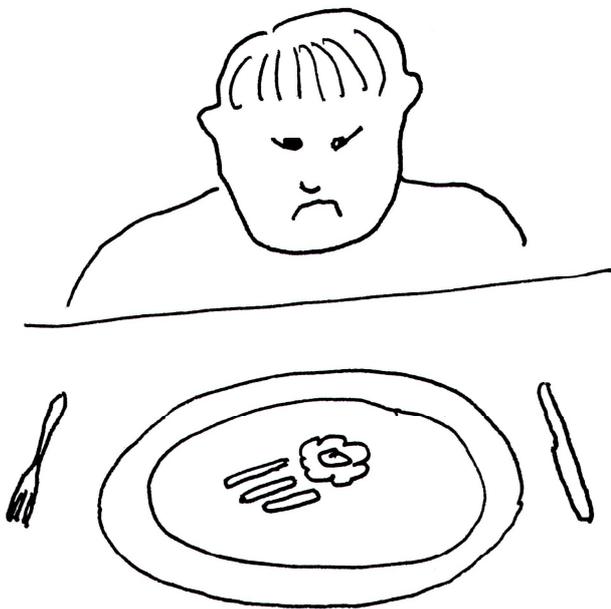


This gives her time to prepare her body.

FIRM TOUCH IS LESS PAINFUL THAN LIGHT TOUCH.

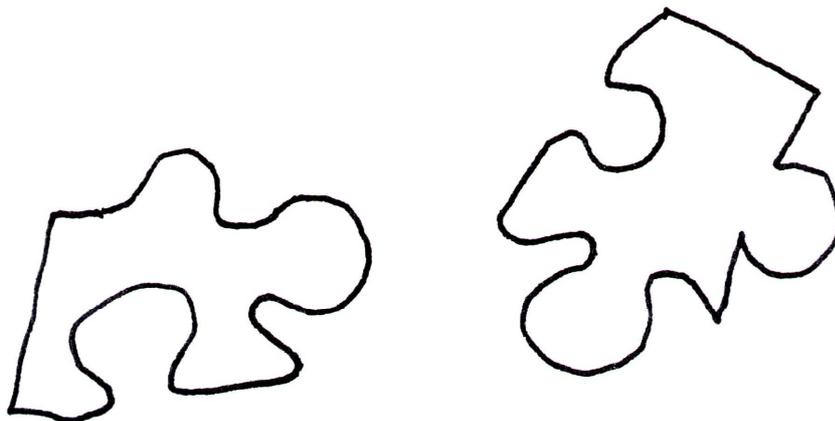
Smell and Taste

Some smells are lovely for us
But
DISGUSTING
For
someone who is hypersensitive to smells!



Some tastes are
REPULSIVE!
To someone who is
hypersensitive
to taste!

Each person with ASD is different. We have to work out where each piece of the jigsaw fits in.



Speech

Speech is a problem!



I can hear the first word and sometimes the last but in between it sort of

S
L
I
P
S

away.

Always use simple speech.

Always speak quietly

Accompany with gestures! (Signs may be too abstract).



Let Ann know what you intend doing before you do it. Wait for her to nod. Then you know that she knows what you are trying to do.

USE YOUR HANDS TO TALK.

Emotional Overload

Instead of feeling happy when someone smiles at Di, she feels pain. The feedback of warmth we feel when we make eye contact, hurts her – some people experience “feeling” as agonisingly painful.

If Sian looks away when you look at her, do not insist on eye contact.

It will help her if you look away when you speak to her.

Eyeball to eyeball contact causes stress and pain to some people with ASD.

Yasmin bites her Mother when her Mother tries to hug her, She wants to be hugged but feels she is being drowned in a tidal wave of feeling.
Keep it cool!



What's Happening?

She lives in a scrambled world. She can't make sense of it. Even though she can say words like, "tomorrow", "yesterday", "Tuesday", "next week", she does not understand the "intervals" involved.

In order to take part in her life, Sue needs to know:

Who will be around.

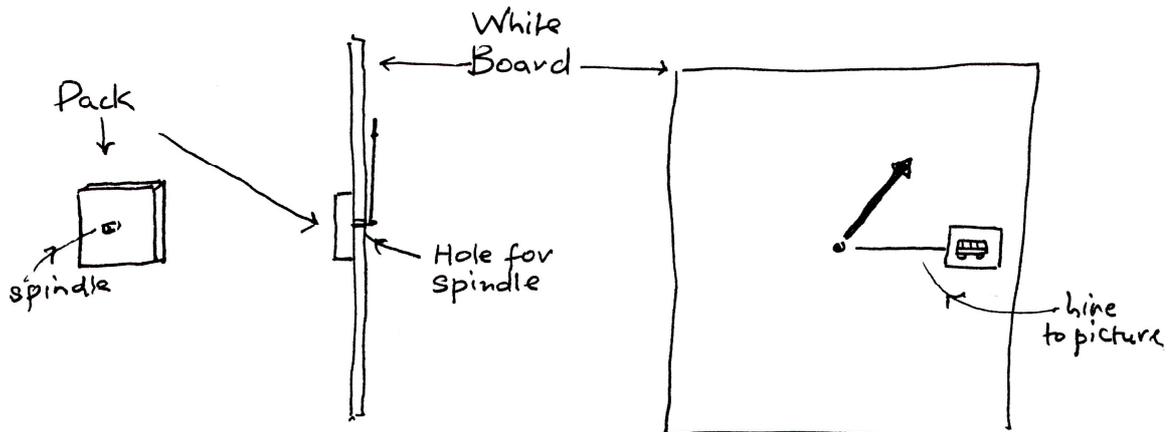
What is happening.

When it will happen.

Sue needs telling in a way she will understand.

1. Clock

Buy a pack of electric works of a clock and the hands from a watchmaker.



Drill a hole in the centre of the board and insert spindle.

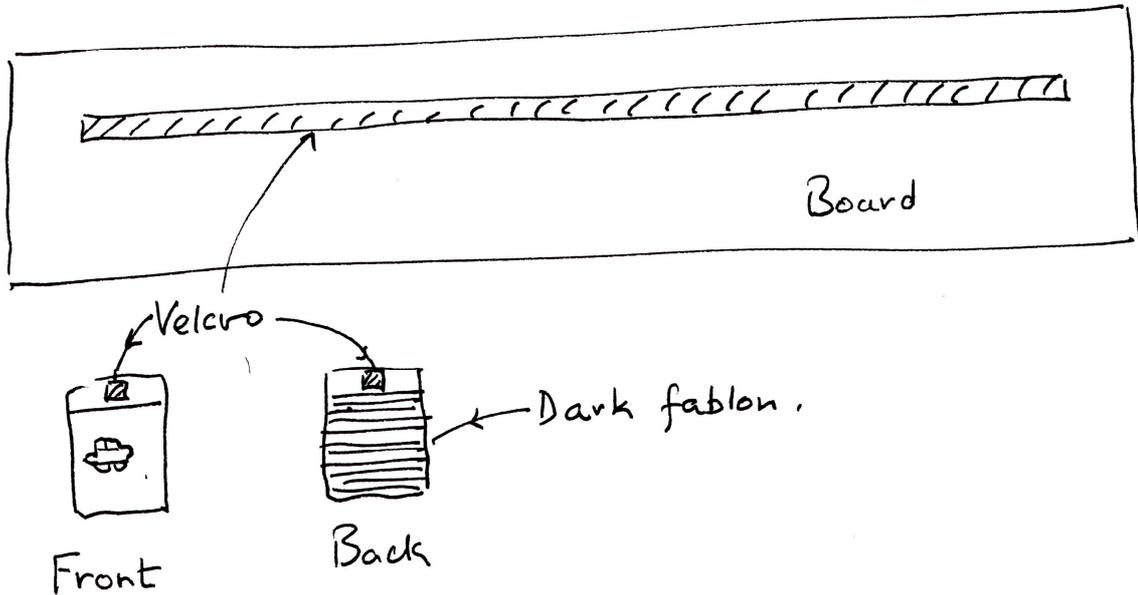
For a day clock, throw away the minute hand.

For an hour clock, throw away the hour hand.

Do not put figures on the clock. Start with one picture.

Use white, self adhesive Velcro so it does not distract attention from the picture.

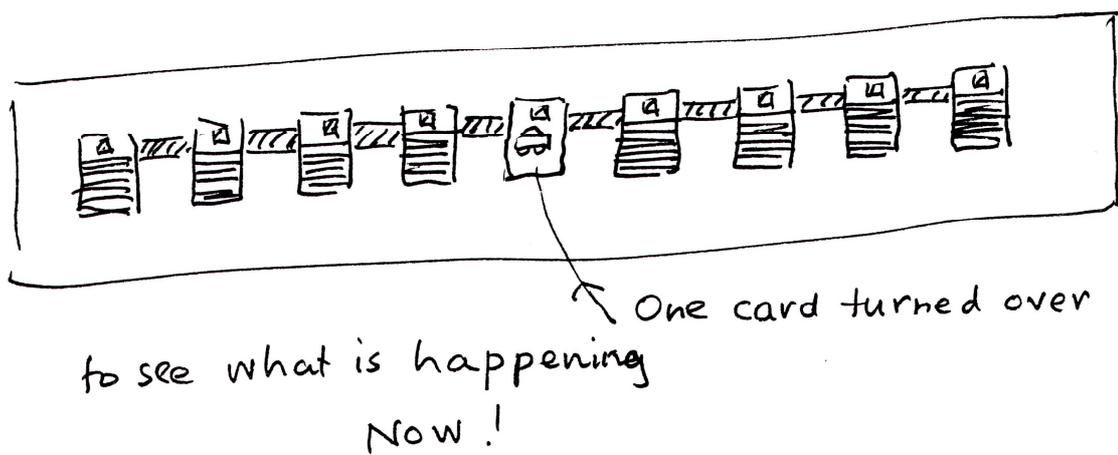
2. Day Timetable.



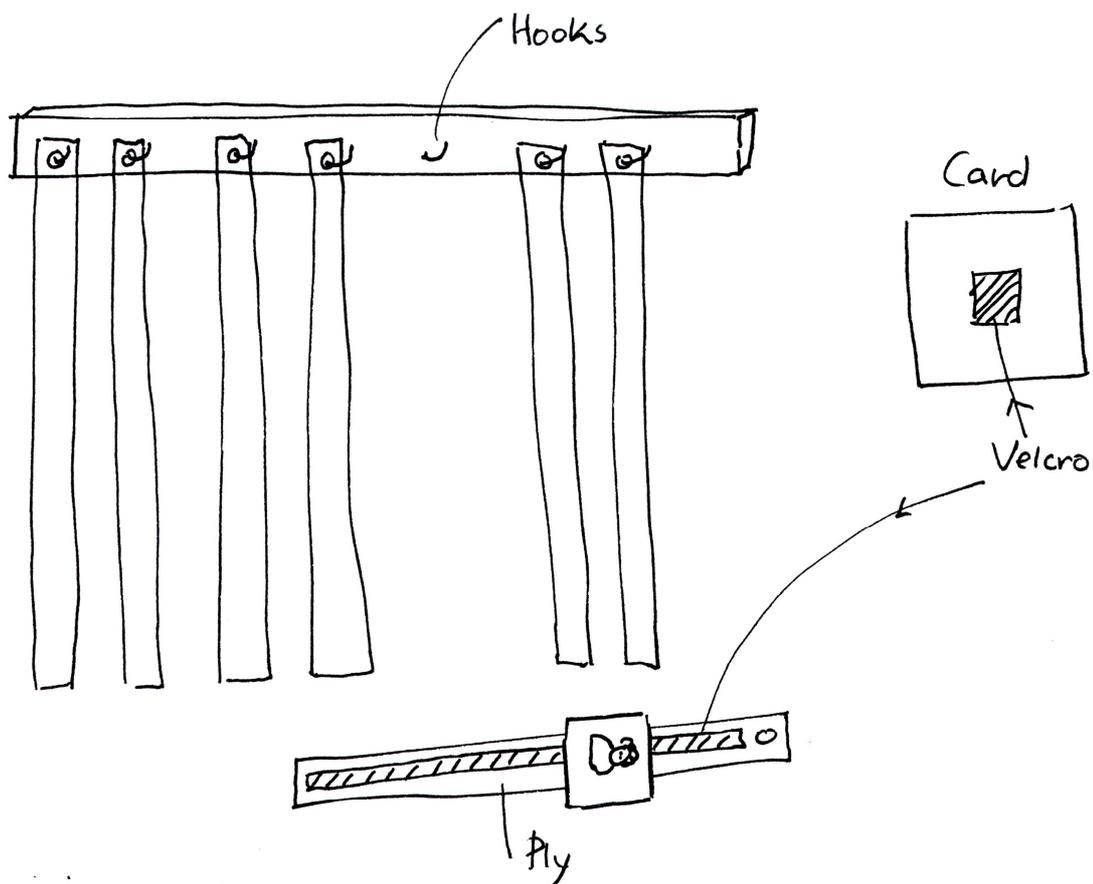
Pictures on front of card.

Fablon on back.

Velcro both sides so the card can be turned over.



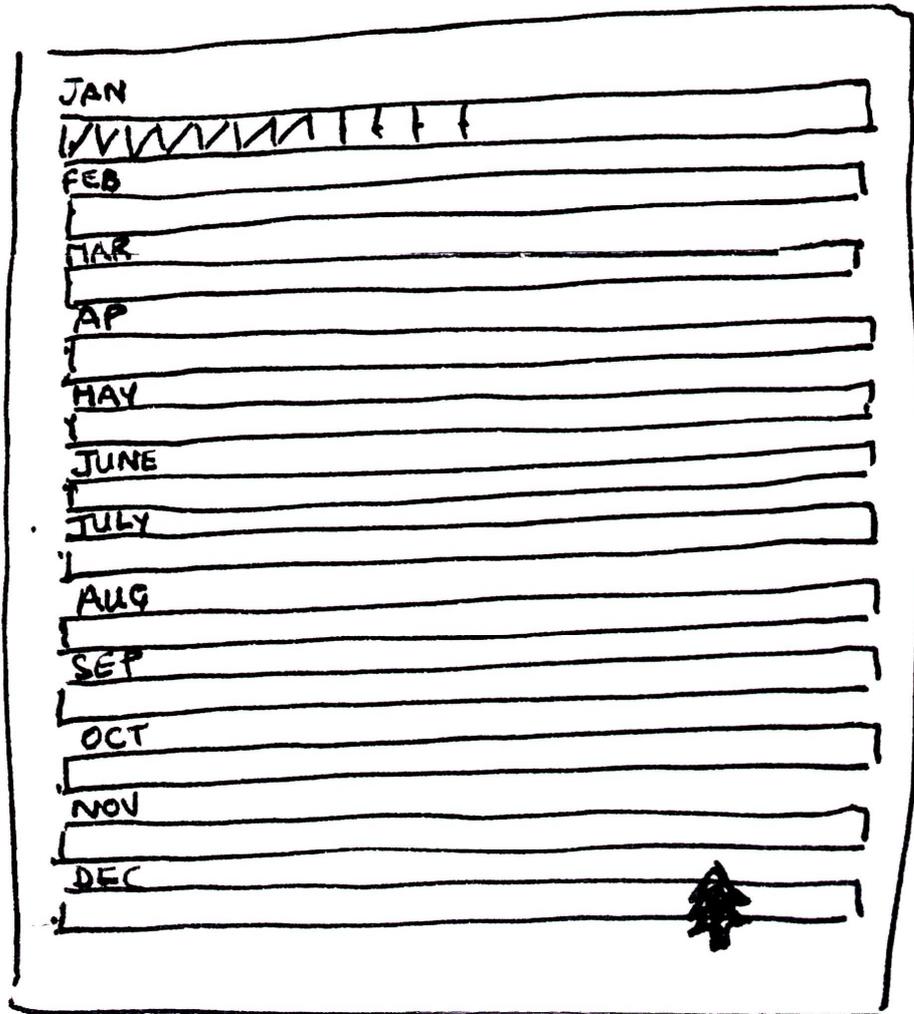
3. Weekly Timetable



This timetable can be used for pictures of both people and activities. The important thing to get over is the difference between “now” and “not now”

4. Year Calendar

Use an office calendar and “split” the months to make it easy to see where you are:

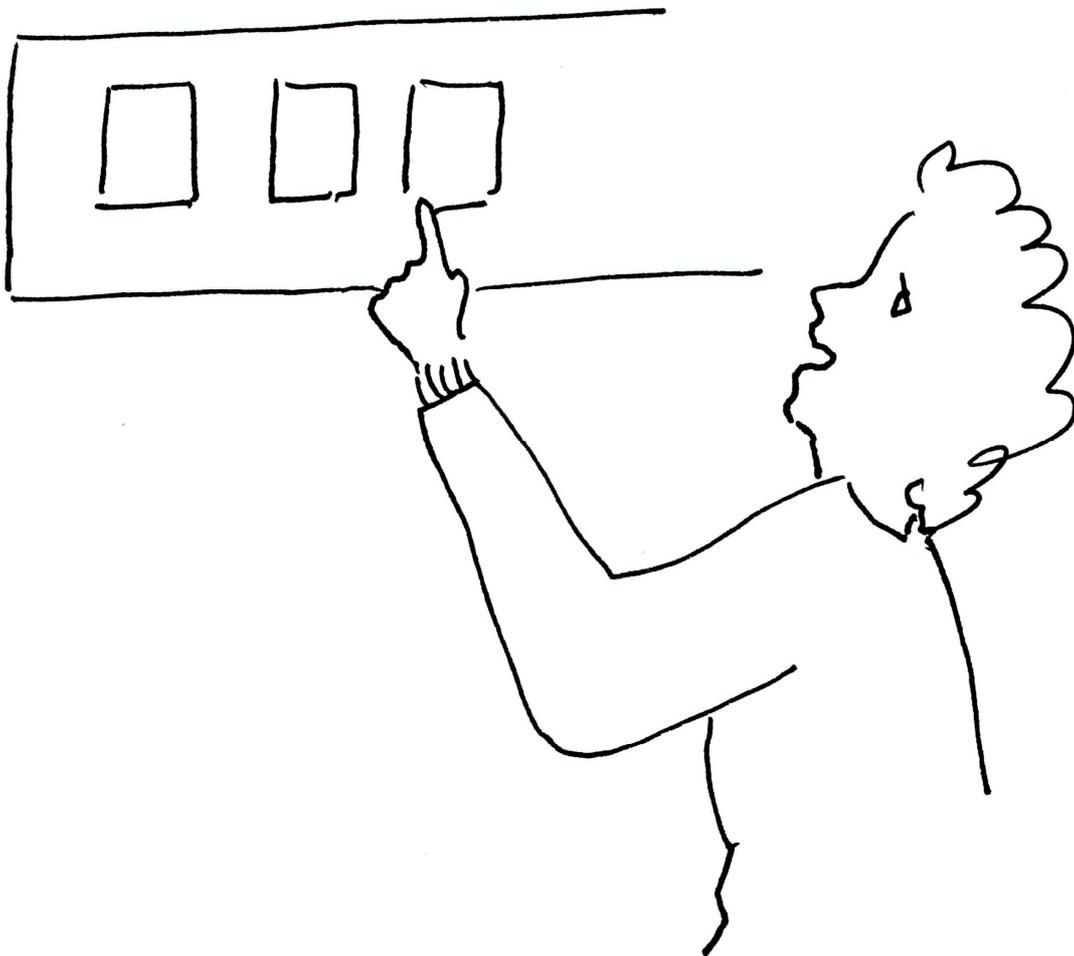


Cross off one day at a time. Make special dates, for example Christmas tree for Christmas.

These special clocks, timetables and calendars help people to know what is going on at any time.

Put them where they can be used all the time, to negotiate and aid understanding.

Use the same system at home and the day centre, otherwise they may look in the wrong place for information.



Choices

can be very difficult

they double the amount of visual processing.

Change of programme

is always stressful.

Sarah has just about worked out what is happening and then it



She knows that she is going for a walk, but does she know that she is coming back? You may have to show her by gesture that as well as going out she is returning to the place she knows.

SCHOOLS ARE HARD!

TOO MUCH

STIMULATION

Especially

IN THE LARGE

**ECHOING
HALL**

are TERRIBLE
NOISE
SUPERMARKETS
TOO MUCH
VISUAL
STIMULUS
HIGH FREQUENCY SOUND
people

KEEP LIFE SIMPLE
LEARN THE LANGUAGE