**The Communication Passport**

A communication passport is a template intended to help those with Rett Syndrome communicate their needs and to share their likes, dislikes, preferences and so on.

Alongside the hospital passport, this document can make transitions into difference places of care easier and enable new people, including medical professionals, to get to know your child.

The template which follows is adapted from a communication passport produced for an

individual girl with Rett Syndrome. The examples included are to provide a sense of how to complete the passport, but of course should be adapted for your own child and are only a starting point.

The contents list (‘Sections in this folder’) is also adaptable – add or subtract sections in whatever way makes sense.

The pages can be printed and put in an A5 binder to be put in your child’s bag or attached to their wheelchair. This should make it easy to add and amend pages and sections as needed.

SECTIONS IN THIS FOLDER

SUGGESTED HEADINGS BELOW. PERSONALISE AS NEEDED.

1. About me

* My family
* Things you should know about me
* What people like & admire about me
* Things you might notice about me
* My seizures

1. Communicating

* How I communicate

1. Likes/dislikes

* What makes me happy
* Things I dislike
* How to help me if I am unhappy

1. Aids and equipment I use

* Aids & equipment descriptions
* How I get around
* How my wheelchair works

1. Daily routines

* My daily routine
* How I get dressed
* Any additional sections as required (eg My sleep support system, My physiotherapy programme, etc)

1. Eating/drinking

* How I eat and drink
* What I like to eat and drink
* The tube in my tummy

1. Medicines

* My medicines

1. Background Information

* My diagnoses
* What is Rett Syndrome?
* My hospital admissions
* Important contacts

ABOUT ME

Hello.

My name is

NAME

PHOTO

MY FAMILY

I live with [family members] in [place].

Here I am with my family.

PHOTO HERE WITH FAMILY

THINGS YOU SHOULD KNOW ABOUT ME

I am [AGE] years old.

[Introductory para if wanted]

I was diagnosed with RETT SYNDROME when I was [age]. This means that: [DESCRIBE AS REQUIRED]:

* ability to sit
* ability to stand/walk
* ability to speak/verbalise/communicate
* ability to use hands
* ability to eat and drink
* ability to perform any self-help tasks

*BUT I can understand you!*

*Please talk to me and treat me in the same way as you would treat anyone else my age.*

WHAT PEOPLE LIKE AND ADMIRE ABOUT ME

PERSONALISE AS NEEDED. EXAMPLES BELOW.

* *My smile*
* *My eyes, and the way I can ‘talk’ with them*
* *My friendliness and interest in people*
* *My sense of humour*
* *My determination to be heard, and to let you know what I want*
* *My strong opinions on what I like and dislike*
* *My engagement in the world around me – I like to be involved and included*
* *My enjoyment of . . .[music/songs/animals etc]*

THINGS YOU MIGHT NOTICE ABOUT ME

PERSONALISE AS NEEDED. EXAMPLES BELOW.

[describe the physicality, frequency, whether this is something which does/doesn’t bother the person, and what someone can do to help when this occurs]

Example:

*Absences: sometimes I can become ‘absent’ for several seconds and my mouth has some contortions which I can’t control. It might be hard to get me to focus or respond, or to do anything else like eating or drinking.*

*This doesn’t bother me but I find it hard to do anything else when this is happening.*

*Please give me time to come through this, don’t try to get me to do anything else whilst it is happening.*

[other possible symptoms to describe: tremors, seizures, breathing, stiffness, muscle spasms, repetitive hand movements]

MY SEIZURES

*I started having seizures in [date]…*

ADD DESCRIPTIONS OF WHAT MY SEIZURES LOOK LIKE, HOW THEY AFFECT ME AND WHAT NEEDS TO BE DONE

ADD DETAILS OF ANY RESCUE MEDS OR EMERGENCY HOSPITAL ADMISSIONS

COMMUNICATING

HOW I COMMUNICATE

PERSONALISE AS NEEDED. EXAMPLES BELOW.

*I can understand what you say.*

*Please look at me when you are talking to me. Please remember that I can understand what what is being said around me.*

*Please talk to me as you would talk to another child of my age.*

*My responses can be quite delayed, so please give me plenty of time to answer your questions.*

*When I want to say YES I will . . .*

*When I want to say NO I will . . .*

*I can make choices between things by . . .*

*When I am really interested in something or someone, I will . . . .*

*When I am happy or excited I will . . .*

*When I am cross/sad/in pain, I will. . .*

*I can use an eye-gaze/button/switch to . . .*

LIKES AND DISLIKES

WHAT MAKES ME HAPPY

PERSONALISE AS NEEDED. EXAMPLES BELOW.

Listening to MUSIC*. My favourite band/singer/song is . . .*

Watching television*. My favourite shows are . . . .*

Reading stories*. My favourite stories are . . .*

Eating and drinking*. My favourite food and drinks are . . .*

Going out. *My favourite places are . . . I like to go to . . .*

People*. I like spending time with* *time with . . .*

Activities. *I like going/doing . . .*

THINGS I DISLIKE

PERSONALISE AS NEEDED. EXAMPLES BELOW.

* The sun in my eyes
* Being too hot
* Loud noises
* Physiotherapy
* WAITING for anything!
* Being ignored
* Being told to calm down
* Being in enclosed, crowded places
* Too many demands at once – I prefer to focus on one thing one at a time
* Being talked down to as if I don’t understand or am a baby
* Being spoken over the top of as if I am not here or don’t have my own opinions

HOW TO HELP ME IF I AM UNHAPPY

Introductory para

[Example: I am good at letting you know if I am unhappy, uncomfortable, frustrated or bored. But it isn’t always easy to tell which of these it might be!]

If I am in pain, I…

[Example: I tend to make an unusually high-pitched sound, and to be a bit shaky. It is fine to give me 10ml of paracetamol or ibuprofen if you think I need it.]

If I am cross, I . . .

If I am bored, I . . .

If I am sad, I . . .

If I am tired, I . . .

The following things often help if I am unhappy or agitated [examples below]:

* A change of scene
* My favourite music/TV show
* Time away in a quiet room (with music or TV)
* A cuddle/attention

AIDS AND EQUIPMENT I USE

AIDS AND EQUIPMENT

[aid/equipment + what it is needed for]

PERSONALISE AS NEEDED. EXAMPLES BELOW.

Ankle foot orthoses (AFOs): I wear these all day to support my ankles and keep my feet straight and uncurled.

Arm-braces: I wear these to stop my hands going into my mouth – while I am eating, and when I am concentrating on activities at school.

Standing frame: I spend time in a standing frame most days, either at home or at school, to help me bear weight and to straighten my spine.

Sleep support system: I have a soft foam sleep support system to keep my hips and knees in a straight line while I sleep and stop my hips hurting.

Eye gaze device: I use my eye gaze to let you know how I am feeling or to make choices

HOW I GET AROUND – MY WHEELCHAIR

PROVIDE DESCRIPTION including how to get person in and out of chair, how the wheelchair works and any particular features.

EXAMPLES BELOW.

*I rely on my wheelchair to move around.*

*I am hoisted in and out of my chair at school and at respite. At home, my mum and dad sometimes lift me.*

*I need to be positioned carefully, with my bottom at the back of the seat, my head on the head-rest and my feet in the foot-plates.*

*I have a tendency to lean to the left when I’m sitting. The side supports help me to sit up straight.*

*I have a waist strap and a chest harness. I need both of these to be secured if I am travelling in a vehicle in my chair, but I can sit quite well with only the waist strap when not travelling.*

HOW MY WHEELCHAIR WORKS

PROVIDE DESCRIPTION. EXAMPLE BELOW.

*The whole seat of my chair tilts back easily, which is useful for positioning me in the chair (with my bottom right at the back) and for letting me relax a bit when I am tired.*

*To tilt the seat: put your foot on the pedal that is between the back wheels, and press down with the handle.*

*To put on the brakes: there are two brakes, one beside each of the back wheels. Please make sure that BOTH brakes are on, and that they are pushed as far as they will go, in order to hold the chair securely.*

*I sit in my chair on the school bus and other transport.*

DAILY ROUTINES

MY DAILY ROUTINES

PERSONALISE AS NEEDED. EXAMPLES DESCRIPTIONS BELOW.

MORNING ROUTINE:

*I wake up at:*

*I get up at: (school days/weekends)*

*When I wake up I like to [listen to my favourite music/watch TV/have someone come and keep me company]*

*When I get up I need to:*

* *have my pad changed*
* *have my medicine through my tube*
* *have my face washed with a flannel*
* *have my teeth brushed*
* *be helped to sit up in bed*
* *be helped to get dressed (Please see notes on getting dressed)*
* *have a tube pad put around my button (a patterned disc with a popper, to stop the button rubbing against my tummy)*
* *have my hair brushed and tied back (I don’t enjoy this and get quite grumpy, so please don’t take too long!)*
* *be positioned in my chair*

BEDTIME ROUTINE:

*I go to bed at . . .*

* *Run my bath – I like lots of bubbles!*
* *Check the area of my tummy around my tube, and clean with a gauze pad if necessary*
* *Give medicine through my tube*
* *Wash me with showergel – especially the area under my chin and in my neck, where food sometimes goes*
* *Brush my teeth while I’m in the bath*

*When you settle me into my bed, make sure that:*

* *My legs and feet are positioned in my sleep support system*
* *My feeding pump is set*
* *The head of my bed is raised a little*

*I like to have someone lie down next to me and read to me to help me fall asleep.*

*I like Charlie and Lola stories best.*

*Usually I fall asleep very quickly but if it takes a bit longer you need to keep reading to me!*

HOW I GET DRESSED

PERSONALISE AS NEEDED. EXAMPLES BELOW.

During the day:

*I wear a spinal brace under my clothes. The brace is in two pieces, to make it easy to put on.*

*The first thing to put on is a vest, which goes underneath my brace. My vests have a hole cut in the middle for my tummy tube. I always wear a special circular pad around my button, to protect my skin. The rest of my clothes go over the brace.*

ADD PHOTOS WHERE THIS HELPS WITH DESCRIPTIONS

*I wear AFOs to support my feet and ankles. I wear KNEE SOCKS underneath the AFOs and shoes on top.*

At night:

*I wear ANKLE SOCKS with my pyjamas in bed. This is partly to keep me warm – I have poor circulation, and my feet are often quite chilly – and partly to prevent pressure on my heels from my sleep system.*EATING AND DRINKING

HOW I EAT AND DRINK

PERSONALISE AS NEEDED. EXAMPLES BELOW.

*I eat orally during the day, as much as I can, and I get extra calories at night via my tube.*

*I am unable to swallow liquids, so water and medicines all go through my tube.*

*My food has to be very soft – like the texture of creamy mashed potato. I can’t manage mixed textures.*

*It can take me quite a long time to eat a small quantity, because I chew and swallow slowly.*

*I sit in my wheelchair for meals. I am pretty messy, so you need to cover me and my chair up before I start eating!*

*I eat my food from a normal teaspoon. I can’t hold the spoon, so I need someone to help me eat.*

*When I have had enough, I persistently look away and keep my mouth closed.*

WHAT I LIKE TO EAT AND DRINK

PERSONALISE AS NEEDED. EXAMPLE DESCRIPTIONS BELOW.

*I eat all kinds of food: as long as it can be whizzed smooth enough in the blender, it is okay.*

*I like a wide variety of tastes, and I’m not too fussy. I particularly like . . . !*

*Some of my favourite foods/drinks are:*

*Foods/drinks I don’t like:*

*Textures I don’t like:*

THE TUBE IN MY TUMMY

PERSONALISE AS NEEDED. EXAMPLE DESCRIPTION BELOW.

*I had a gastrostomy to insert a feeding tube in [date]. It was changed to a [Mini/Mic-Key] button in [date].*

*I had the tube put in place because I have trouble drinking more than a few drops of liquid orally, and I wasn’t managing to take all my medicines. I also struggle to eat enough orally to help me grow.*

*The tube is used now for medicines, water, blended food and night-time tube-feeds to give me extra calories.*

*Button details:*

*[Type and size of button]*

*Feed details:*

*[Type of feed]*

*[Volume given, at what times, at what rate if via pump]*

MY MEDICINES

I take the following medicines each day.

|  |  |  |  |
| --- | --- | --- | --- |
| Name of medicine, what it is given for and when it was first prescribed | Time of day | Dose | Method |
| *Example: Sodium Valproate, for epilepsy, started Feb 2013* | *Example: 7am* | *Example:.*  *10mls* | *Example:*  *Orally by syringe* |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |

BACKRGOUND INFORMATION

MY DIAGNOSES

I have been diagnosed with the following conditions:

PERSONALISE AS NEEDED. EXAMPLES BELOW.

*Rett syndrome: Diagnosed in [date of clinical/genetic diagnosis] (mutation: add specific MECP2 mutation if known)*

*Gastro-oesophageal reflux:*

*Diagnosed when I was [age], treated with [names of medicines]*

*Scoliosis: Diagnosed when I was [age], progressive right-sided thoracic neuromuscular curve, kept under regular review at [name of hospital]*

*Epilepsy: Diagnosed when I was [age], symptomatic generalised epilepsy, treated with [name of meds], kept under regular review at [name of hospital]*

*Dystonia: Diagnosed when I was [age], evolving motor disorder, treated with [name of meds], kept under regular review at [name of hospital]*

WHAT IS RETT SYNDROME?

Rett syndrome is a complicated neurological disorder caused by a faulty gene. (The gene is called MECP2.) It is usually caused by a random genetic mutation, not a gene that is carried in families.

The mutated gene has switched off a vital protein in my brain, and interrupted the connections between neurons.

It is as if the connection between my brain and my body has been switched off, so I can’t make my body work the way my brain wants it to.

*That’s why I can’t sit, stand, walk, talk or use my hands.* [AMEND AS NEEDED]

*It affects all kinds of things, including my spine, breathing and digestive system*. [AMEND AS NEEDED]

MY HOSPITAL ADMISSIONS

|  |  |  |
| --- | --- | --- |
| Date | Reason for admission | Details |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
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|  |  |  |
|  |  |  |

IMPORTANT CONTACTS

Complete with relevant people’s details, add rows if needed.

|  |  |  |
| --- | --- | --- |
| Person | Phone Number | Address |
| Mum (name) |  |  |
| Dad (name) |  |  |
| School |  |  |
| GP (name) |  |  |
| Pediatrician  (name) |  |  |
| Spine surgeon (name) |  |  |
| Neurologist  (name) |  |  |