

MY HEALTH PASSPORT

First name

Last name

I like to be known as

Please ensure I take this
with me when I leave



RETT UK HEALTH PASSPORT



Guidance Notes

We hope you are pleased with your Health Passport and find it is a really useful resource whether you are just visiting hospital as an outpatient (the Grab Sheet may be more appropriate here), as an inpatient or unplanned emergency admission. It will quickly help the staff involved in treating your child or the person with Rett syndrome you are supporting, to have an overview of their needs and treat them accordingly.

We have produced this Health Passport in a format that allows you to complete it on your laptop, PC or tablet and then print it out. It is a living document and should be updated whenever circumstances change.

We suggest that once you have completed the health passport and have saved a copy of it electronically, you print it off and put it in an A4 folder. The display folders with clear pockets will work well for this or a ring binder but that is slightly more bulky. You can then take this with you to hospital or other medical appointments as needed e.g. GP, dentist.

We have added the Grab Sheet at the beginning. This is essentially a quick view summary that you can hand to the staff on A & E if an unplanned admission. Then, if an admission is needed, you give them the full health passport to go with their notes.

We have also added in a page for Dental Health which you can just take out and use on visits to the dentist as needed although they also normally ask about what medication the person is on so you may find the Grab Sheet useful here too.

There is also a page called Hospital Diary & Notes. We suggest you take this out and keep this separate from the hospital passport so you can make a note of fluid intake, bowel movements etc. This should be recorded by hospital staff but it is helpful to do this so that there is a complete record of these things and indeed, anything else that you may want to recall later.

If you have current photos and even video of your child or the person you are supporting on a smart phone it is helpful to show these to the people involved in their care. It shows how the person they are treating is when they are well and the quality of life they normally experience.

We have limited the size of the boxes because if you make this too long it is less likely to be read thoroughly. Try to keep the statements succinct - bullet points may be useful to use. If you feel it is necessary to expand on any points this can be done on the notes page.

As always, we would love to have your feedback including any suggestions for amendments. Please email support@rettuk.org.

ACCIDENT & EMERGENCY GRAB SHEET



Guidance Notes

The A&E grab sheet has been developed to aid quick information handover in an emergency situation.

This is not designed for the individual but follows clinical need. Therefore, the care provider, keyworker, family member or other appropriate person will need to fill the information out and keep it updated.

The format is in a traffic light system which is universally accepted by Health Professionals and is easy to use.

Please ensure a copy is kept with the individual if they are attending day services or activities outside their home environment.

It is recommended that the 'Grab Sheet' is completed electronically as this would ensure that the document is kept current and duplicate copies can be printed when necessary.

Once in hospital the 'Grab Sheet' may be stapled to the individuals' notes and follow them throughout their journey. This means that there may be situations where they are not returned. Staff supporting the individual can ask for the 'grab sheet' to be returned on discharge.

At any point you can indicate where further information is in the Health Passport, however if space allows please re-write the information from the Health Passport into the 'Grab Sheet', this will aid in quick information hand over. For up to date information on Regular Medication it may be best if the MARS sheet or medication record card is brought in to hospital.

These guidance notes and the grab sheet are based on a format developed by the LD Liaison Nurses in Buckinghamshire Healthcare NHS Trust

ACCIDENT & EMERGENCY GRAB SHEET

Please keep updated in case of emergency admission to hospital.

ATTACH
PHOTOGRAPH
HERE



Things you **must know** about me



Things that are **important** to me



My **likes and dislikes**

Name

Preferred name

Address

Telephone

Next of kin

Next of kin's contact number

Main carer

Main carer's contact number

GP's name

GP's Address

GP's telephone number

Community learning
disability nurse

Care manager/social worker

Psychiatrist (if applicable)

Other (relevant)

Medical History/ Pre-existing medical conditions

(e.g. epilepsy, diabetes, high blood pressure). If epilepsy, describe type of seizure

Regular medication

How medication is taken

Things that make me anxious

(things that I will not tolerate, e.g. needles, BP cuff, white coats, noise)

How to help me feel safe and calm about my anxieties

Mental capacity

(please state if you are already aware of areas where I will need support in decision making or if a DNACPR is already in place)

Method of communication

[Text input field]

The best way to give information

[Text input field]

The best time to give information

[Text input field]

Method of expressing pain (e.g. shouting, crying, grinding teeth)

[Text input field]

Likes (e.g. quiet room, personal items/possessions)

[Large text input area]

Additional health needs Please specify additional equipment required to support me

[Large text input area]

Hearing difficulties Yes No Vision difficulties Yes No

Wheelchair user Yes No Uses hoist Yes No

Other mobility aids

[Text input field]

Dislikes (e.g. certain foods or colours, etc)

[Large text input area]

Allergies (e.g. penicillin, plasters, latex)

[Text input field]

Special dietary needs (e.g. diabetic, gluten free, soft foods, risk of choking, specialist equipment needed)

Eating

[Text input field]

Drinking

[Text input field]

Additional information

[Large text input area]

Keeping safe (e.g. bed rails, water temperature, wandering)

[Text input field]

Further information may be found if I have a completed **Health Passport** book. Please contact the **Learning Disability Nurse** or their equivalent on

[Text input field]

Completed by

[Text input field]

Date completed

[Text input field]

MY HEALTH PASSPORT

This is for people that support me. It contains important information about me.

My name is

ATTACH MY
PHOTOGRAPH
HERE

This passport belongs to me. Please remember to update information as and when it changes.

Please keep this with my notes but do remember to return it to me when I am discharged. Thank you.

Please look at my passport, before any intervention with me as this is important to me.



Things you must know about me



Things that are important to me



My likes and dislikes

ABOUT RETT SYNDROME

Rett syndrome is a rare and complex neurological disorder which mainly affects females. It is caused by a mutation on the X Chromosome in a gene called MECP2. After a period of near normal development, children with Rett syndrome will experience a regression and where the majority will lose key skills including purposeful hand use, walking and talking. Additional co morbidities occur including breathing and feeding problems, epilepsy, autonomic dysfunction, gut/bowel problems, orthopaedic issues including scoliosis, hip displacement and fractures.

Much of the literature you will find on Rett syndrome is not as up to date as we would like so please do refer to a reliable source for more information. Rett UK has been providing support to families and professionals for over 30 years. Please do call us or use the information on our web site for further advice.

Rett syndrome is not a neuro degenerative disorder and people with Rett syndrome do generally have a very good level of understanding. Please be aware of this and respect this when communicating with the patient.

People with Rett syndrome can have other problems just like the general population so please look beyond the label and treat accordingly.

Tarquinio et al, The Changing Face of Survival in Rett Syndrome and MECP2-related Disorders, June 2015, found that survival for classic and atypical RTT was greater than 70% at 45 years.

Whilst people with Rett syndrome do share many comorbidities, there is a spectrum of severity and not every patient will have all symptoms. The family and carers will be a huge source of information with regard to your patient so please consult with them and involve them in all decisions.

ABOUT RETT UK

Rett UK has over 30 years of experience, providing the emotional and practical support needed to deal with the everyday challenges that Rett syndrome presents. A national telephone helpline answers calls from desperately worried parents, not just at the point of diagnosis but also at key transitions and moments of crisis. Local family led support groups and a parent-to-parent contact network provide the contact with other families that is so crucial in reducing isolation.

Access to high quality seminars from the UK's leading experts on Rett syndrome at Regional Days and Family Weekends provides families with up to date, accurate information in subjects like epilepsy, spinal surgery and communication, helping them with management of the disability.



Rett UK Ltd, Victory House, Chobham Street, Luton, Bedfordshire LU1 3BS
General Enquiries: 01582 798 910 / info@rettuk.org • www.rettuk.org

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THINGS YOU MUST KNOW ABOUT ME



My name

I like to be known as

My NHS Number

My date of birth

My address

 Postcode

My telephone number



Summary of my medical history including any surgery

Completed by

Date completed

THINGS YOU MUST KNOW ABOUT ME



My current medication



How I communicate



Help with making decisions

NB: Please follow the principles of the Mental Capacity Act, even if lack of capacity is established please support me to be involved as much as possible. For more information please refer to www.nhs.uk/conditions/social-care-and-support/mental-capacity

I need someone who knows me well to help me make decisions. That person is



Social circumstances e.g. lives with parents, supported living, residential home etc.



Family contact person, carer or other support

Their relationship to me e.g. Mum, Dad, Home Manager, Support Worker

Address

Postcode

Telephone number

Completed by

Date completed

THINGS YOU MUST KNOW ABOUT ME



Second (optional) family contact person, carer or other support

Their relationship to me e.g. Mum, Dad, Home Manager, Support Worker

Address

Postcode

Telephone number



My support needs and who gives me the most support



The language my carer speaks is (e.g. English, French etc.)



My religion

My religious/
spiritual needs

My ethnicity

Completed by

Date completed

THINGS YOU MUST KNOW ABOUT ME



My GP

Address

 Postcode

Telephone number

Other services/professionals involved with me



School/college I attend

Address

 Postcode

Telephone Number



Day service

Address

 Postcode

Telephone number

Completed by

Date completed

THINGS YOU MUST KNOW ABOUT ME



Respite service

Address

Postcode

Telephone number



Allergies I have including special dietary needs



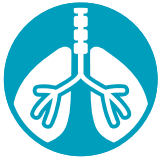
Medical interventions - how to take my blood, give injections, BP etc.

NB: Typically people with Rett syndrome have small veins that tend to collapse easily so taking bloods can be difficult. The best place normally to try for me is:

Completed by

Date completed

THINGS YOU MUST KNOW ABOUT ME



Heart and/or breathing problems

NB: Long QT syndrome does occur in some people with Rett syndrome. Please check before you give me certain medications.



Large empty rectangular area for notes related to heart and/or breathing problems.



Risk of choking, dysphagia (eating, drinking and swallowing)

NB: Please be aware that aspiration is a high risk in people with Rett syndrome. Check my history of this and position accordingly.

Large empty rectangular area for notes related to risk of choking, dysphagia (eating, drinking and swallowing).

Completed by

Date completed

THINGS YOU MUST KNOW ABOUT ME



My treatment plan for existing conditions

Blank area for writing the treatment plan for existing conditions.



What to do if I am anxious

NB: People with Rett syndrome are often highly anxious individuals. My anxiety can make my breathing worse and my hand stereotypies more intense.

Blank area for writing what to do if the user is anxious.

Completed by

Blank space for the name of the person who completed the passport.

Date completed

Blank space for the date the passport was completed.

THINGS THAT ARE IMPORTANT TO ME



How to communicate with me

NB: People with Rett syndrome generally have very good understanding so please be aware of this. Do not talk over me and be careful what you communicate around me.

Blank area for notes regarding communication preferences.



How I communicate with you

Blank area for notes regarding how the user communicates with others.



How I take medication (whole tablets, crushed tablets, injections, syrup)

Blank area for notes regarding medication preferences and administration.



How you know I am in pain

NB: People with Rett syndrome typically have a high pain threshold.

Blank area for notes regarding pain recognition and thresholds.

Completed by

Blank field for the name of the person who completed the form.

Date completed

Blank field for the date the form was completed.

THINGS THAT ARE IMPORTANT TO ME



Moving around (walking aids, wheelchair, positioning in bed)

Blank area for notes related to moving around.



Personal care (dressing, washing, etc.)

Blank area for notes related to personal care.



Seeing/hearing (e.g. problems with my sight or hearing)

Blank area for notes related to seeing/hearing.



How I eat (e.g. food cut up, pureed, risk of choking, help with eating)

Blank area for notes related to how I eat.

Completed by

Blank space for name.

Date completed

Blank space for date.

THINGS THAT ARE IMPORTANT TO ME



How I drink (e.g. drink small amounts, thickened fluids)

Blank area for notes regarding drinking habits.



How I keep safe (e.g. bed rails, support with challenging behaviour)

NB: This may not be the same as when in the home setting

Blank area for notes regarding safety measures.



How I use the toilet (e.g. continence aids, help to get to the toilet)

Blank area for notes regarding toilet use.



Sleeping (e.g. sleep system used, sleep pattern/routine)

Blank area for notes regarding sleeping habits.

Completed by

Blank field for name of person who completed the form.

Date completed

Blank field for date of completion.

MY LIKES AND DISLIKES



Things I like (e.g. what makes me happy, things I like to do ie. watching TV, reading, music, routines). Please **do** this:

A large, empty rectangular area with a light green background, intended for writing down things the user likes to do.



Things I don't like (e.g. don't shout, food I don't like, physical touch). Please **don't do** this:

A large, empty rectangular area with a light green background, intended for writing down things the user does not like to do.

Completed by

Date completed

MORE ABOUT ME



Other things you should know about me and how I am when I am well

A large, empty light blue rectangular area intended for writing or drawing, occupying most of the page's content space.

Completed by

Date completed

HOSPITAL DIARY & NOTES



It may be useful here for my parent/carer to record key events (e.g. my fluid intake, bowel movements etc.) in addition to what the hospital is recording.

A large, empty light blue rectangular area intended for recording notes or diary entries.

CONTACTS AND USEFUL WEBSITES



If your local hospital has a learning disability nurse or similar role it would be good to include this here

Rett UK National Telephone Helpline: 01582 798 910 www.rettuk.org

DENTAL HEALTH

This can be taken out and used independently to the health passport but may also be useful to have the Grab Sheet with you for a visit to the dentist as they do ask about current medications.

Name	<input type="text"/>	Preferred name	<input type="text"/>
Address	<input type="text"/>		
	<input type="text"/>		
Postcode	<input type="text"/>	Telephone	<input type="text"/>



My dental hygiene routine is (e.g. I have help to clean my teeth twice a day, I am able/not able to floss. I do/do not use a mouthwash, etc.)



At the dentist I will need help with (e.g. encouraging me to open my mouth, turn my head to one side, etc.)



Things to be aware of whilst I am at the dentist (e.g. I cannot transfer to the chair without a hoist so please allow room for the examination to take place in my wheelchair. I have a sensitive gagging reflex. I am highly anxious about...)



Things you can do to make it easier for me (e.g. please have radio on quietly in the background)

Please refer to my Grab Sheet for list of current medication and any allergies.

Completed by	<input type="text"/>	Date completed	<input type="text"/>
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