MY STORY

NATIONAL PATIENT-HELD FOLDER FOR CHILDREN & YOUNG PEOPLE

MY STORY

Hello, my name is:

I liked to be called:

My date of birth is:

I have an Emergency Care Plan: Yes ○ No ○

I have Allergies Yes ○ No ○

I am Allergic to:

Please use block capitals

PURPOSE OF THE MY STORY FOLDER

The MY STORY folder has been created by the HSE for the purpose of promoting child & family centred communication and coordination of care for children & young people with specific healthcare needs.

The sections within the folder are to be completed by parents/guardians, young people themselves and relevant healthcare professionals.

Every effort should be made to ensure that information contained in the folder is relevant to the current healthcare and support needs of the child or young person.

HOW TO USE THE MY STORY FOLDER

PARENTS/GUARDIANS AND YOUNG PEOPLE:

- A healthcare professional will provide you with the MY STORY folder and explain how to use it.
- All sections of the folder might not be relevant to you straight away, but may become helpful over time.
- Take this folder to all your healthcare appointments, hospital admissions and respite breaks.
- Keep all relevant healthcare documents here, safely and in one place.
- Review information held in the folder at frequent intervals to ensure it is up to date.
- If required, please remind healthcare professionals to fill in the visit summary (Section 4) at appointments.

HEALTHCARE PROFESSIONALS

- Review the MY STORY folder to obtain up to date and relevant information related to this child or young person.
- Provide a copy of all specific guidelines/care plans for this child or young person, relevant to your area of care, for inclusion in their folder.
- Complete the visit/clinic summary sheet (Section 4) at the end of each visit or appointment.
- Send a copy of all your reports or letters to the parent/guardian for inclusion in the folder.
- Use block capitals at all times.

HOMECARE NURSES/CARERS

- Complete the hand-over summary sheet (Section 10) at the end of each shift.
- Use block capitals at all times.

The contents of this folder are available to download and print at **hse.ie/mystory**

MY STORY

Section 1	**My personal details and emergency contacts**
Section 2	**My emergency care plan**
Section 3	**My recent medical history** • summary of my medical history and allergies, completed by my consultant or GP the first time I use the folder
Section 4	**Healthcare professional visit or clinic summary** • summary and recommendations sheet completed after each visit or clinic appointment by the relevant - healthcare professional - multidisciplinary team
Section 5	**Medication management** • my prescriptions • medication instructions • log of medication changes
Section 6	**All about me** • me, my family and what matters to me • my daily routine • my weight and height record
Section 7	**My care plans** • all care plans • home and community programmes
Section 8	**People involved in my care** • contact details for healthcare professionals in hospital and community services
Section 9	**Specific information about my condition** • fact sheets, leaflets and guides
Section 10	**End of shift handover** • summary to be completed by home care nurses or carers
Section 11	**Reports / Letters / Assessments**
Section 12	**Equipment** • home, school and medical equipment
Section 13	**My Appointments** • diary of appointments • questions to ask or concerns
Section 14	**Signature Bank**
Section 15	**Other**

1 MY PERSONAL DETAILS AND EMERGENCY CONTACTS

My personal details and emergency contacts

To be completed by my parent or guardian.

Child's name:	Date of birth:
Address: Eircode:	
Language(s) spoken at home:	Interpreter required: Yes ☐ No ☐ Language:
Medical Card: Yes ☐ No ☐	Long Term Illness Card: Yes ☐ No ☐

Hospital information

Hospital name and address:	Chart or medical record number:

Parent/Guardian information

Parent/Guardian 1	Parent/Guardian 2
Name:	Name:
Relationship to child:	Relationship to child:
Are you legal guardian? Yes ☐ No ☐	Are you legal guardian? Yes ☐ No ☐
Phone number:	Phone number:
Email address:	Email address:
Language(s) spoken:	Language(s) spoken:
Emergency contact: Yes ☐ No ☐	Emergency contact: Yes ☐ No ☐

Significant Carer information

Significant Carer 1	Significant Carer 2
Name:	Name:
Relationship to child:	Relationship to child:
Phone number:	Phone number:
Email address:	Email address:

PLEASE USE BLOCK CAPITALS

2 MY EMERGENCY CARE PLAN

3 MY RECENT MEDICAL HISTORY

Summary of medical history and allergies from my consultant/GP

My recent medical history

Summary of my medical history and allergies.
To be completed by my consultant or GP the first time I use this folder.

Child's name:	Date of birth:
Chart or medical record number:	Gender: M ☐ F ☐

Allergies:	
Primary diagnosis:	
Other medical conditions:	
Current treatments and medication:	
Please detail any recent changes to care plan or medication:	
G.P. ☐ or **Consultant** ☐	Name: (BLOCK CAPITALS) Signature: Date:

PLEASE USE BLOCK CAPITALS

4 HEALTHCARE PROFESSIONAL VISIT/CLINIC SUMMARY

Summary completed by

- healthcare professional
- multidisciplinary team

Healthcare professional visit or clinic summary

To be completed after each visit or clinic appointment by the relevant healthcare professional or multidisciplinary team.

Child's name:	Date of birth:
Chart or medical record number:	Date of visit or clinic appointment:
Type of visit or clinic appointment:	
Healthcare professionals present:	

Current issues:	
Summary of healthcare professional assessment:	
Recommendations and follow up actions:	
Medication changes:	
Healthcare professional:	Name: (BLOCK CAPITALS) Signature: Date:

Parent or Guardian: Please feel free to share this with your GP and other healthcare professionals looking after your child.

PLEASE USE BLOCK CAPITALS

5 MEDICATION MANAGEMENT

- my prescriptions
- medication instructions

Parent or Guardian log of medication changes

Please record instructions given over the telephone or verbally at a visit or clinic appointment.

Date:	Medication advice given:	Advised by: (Name & profession)

PLEASE USE BLOCK CAPITALS

6 ALL ABOUT ME

- me and my family
- my daily routine
- weight and height record

ALL ABOUT ME

Introducing my family

Name:	Relationship:	Contact details:

FAMILY PHOTO CAN BE INCLUDED HERE

PLEASE USE BLOCK CAPITALS

ALL ABOUT ME

Other things that we would like you to know about our family

Other important people to me and to my family

Name:	Relationship:	Contact details:

What matters to me

Things that make me feel good:	
Activities that I enjoy:	
Things I don't like:	
Other things that matter to me:	

PLEASE USE BLOCK CAPITALS

ALL ABOUT ME

How I communicate

How I communicate:	
Specific communication plan in place?	Yes ☐ No ☐ If yes, please see the care plan section of my folder
How you know that I am happy:	
How you know that I am unhappy/sad:	
How you know I am in pain:	
How I can let you how I am feeling about things:	
My Vision:	Good ☐ Impaired ☐
Helpful visual aids:	Glasses: Yes ☐ No ☐
My Hearing:	Good ☐ Impaired ☐
Auditory aids used:	Hearing Aid: Yes ☐ No ☐

PLEASE USE BLOCK CAPITALS

ALL ABOUT ME

How I get my nutrition : Eating / Oral feeding

My mealtime routine at home:	
I can eat independently:	Yes ☐ No ☐
I require the following assistance to eat:	
Foods that I enjoy:	
How I like my food prepared:	
I can drink independently:	Yes ☐ No ☐
I require the following assistance to drink:	Thickener added Yes ☐ No ☐
Drinks I enjoy:	
How I like my drinks prepared:	
Food or drinks I need to avoid:	

How I get my nutrition : Using a tube feed (enteral feeding)

I can have some food orally:	Yes ☐ No ☐
My feed is given via:	Nasogastric Tube ☐ Gastrostomy Tube ☐ Other ☐ Nasojejunal Tube ☐ Jejunostomy Tube ☐ .....
Dressings or Tapes I use:	
The position I need to be in when feeding is:	
Other considerations: e.g venting, medication ports	
Any special requirements:	Yes ☐ No ☐ If yes, please see the care plan section of my folder

PLEASE USE BLOCK CAPITALS

ALL ABOUT ME

My food allergies and / or intolerances

I have food allergies and / or intolerances: Details:	Yes ☐ No ☐
I use an epipen:	Yes ☐ No ☐ If yes, please see the care plan section of my folder
Other important considerations about my allergies and / or intolerances:	

How I empty my bladder and bowel

I require assistance:	Yes ☐ No ☐
At home I use:	Toilet ☐ Commode ☐ Intermittent Catheterisation ☐ Bed Pan ☐ Urine Bottle ☐
I wear nappies:	Day: Yes ☐ No ☐ Night: Yes ☐ No ☐
My toilet or changing routine at home:	Day: Night: Cleansers and barrier creams use: Name:
I use laxatives:	Yes ☐ No ☐ Details:
My normal bowel pattern is:	

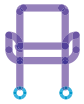
PLEASE USE BLOCK CAPITALS

ALL ABOUT ME

How I get washed and dressed	
I use a bath:	Yes ☐ No ☐ How often? 
I need assistance to have a bath:	Assistance needed: Equipment Used:
I use a shower:	Yes ☐ No ☐ How often? 
I need assistance to have a shower:	Assistance needed: Equipment Used:
Special care required for my skin:	Yes ☐ No ☐ Washes and Creams used:
Additional considerations for skin care:	Describe any other special instructions to help look after my skin:
I need special pressure area care:	Yes ☐ No ☐ If yes, please see the care plan section of my folder
I need assistance with dressing: Additional information:	Yes ☐ No ☐  Times I change my clothes: Day _____ Night _____
How I look after my teeth:	Oral/dental care instructions: 

PLEASE USE BLOCK CAPITALS

ALL ABOUT ME

How I move around	
I need assistance to mobilise or move around:	Yes ☐ No ☐ 
I have a physiotherapy routine at home:	Yes ☐ No ☐ If yes, please see the care plan section of my folder
Mobility equipment that I use in my home and for going outside:	
I wear splints:	Yes ☐ No ☐ Type: Times used each day: For how long:
I have a standing frame:	Yes ☐ No ☐ Type:  Times used each day: For how long:
I need assistance to sit:	Yes ☐ No ☐
I have special seating equipment at home or school:	Yes ☐ No ☐ Type: Seating routine:
Additional information:	

PLEASE USE BLOCK CAPITALS

ALL ABOUT ME

If I need help moving

I may need pain relief medications before lifting or handling Details:	Yes ☐ No ☐	
I require a hoist to lift me:	Yes ☐ No ☐	If yes, please see the care plan section of my folder
I use an all-day sling:	Yes ☐ No ☐	If yes, please see the care plan section of my folder
Important things to remember when you are helping me move:		

My body temperature

My normal temperature range is:		
How I react or look when I have a have a high temperature:		
What medicine works best to get my temperature back to normal: Additional Information:		
I can get cold easily:	Yes ☐ No ☐	
My feet and hands can feel cool:	Yes ☐ No ☐	
Additional information:		

PLEASE USE BLOCK CAPITALS

ALL ABOUT ME

How I sleep	
I have a good sleep pattern:	Yes ☐ No ☐
My routine at home:	Day time: Night time:
What helps me sleep:	
I use a sleep system:	Yes ☐ No ☐ Type of sleep system:
I use a special mattress:	Yes ☐ No ☐ Type of mattress:
I need to be turned during the night:	Yes ☐ No ☐ How often:

ALL ABOUT ME

What I need to help me breathe	
I need some help with my breathing:	Yes ☐ No ☐
I have a tracheostomy:	Yes ☐ No ☐ If yes, please see the care plan section of my folder
I use equipment to help with my breathing:	Yes ☐ No ☐ If yes, please see the care plan section of my folder
Equipment I use as part of my daily routine:	Nebuliser ☐ Suction Machine ☐ Oxygen ☐ BiPAP/CPAP ☐ Cough Assist ☐ AIRVO ☐ Other:
Equipment I use when I am unwell:	Nebuliser ☐ Suction Machine ☐ Oxygen ☐ BiPAP/CPAP ☐ Cough Assist ☐ AIRVO ☐ Other:
I have a respiratory care plan:	Yes ☐ No ☐ If yes, please see the care plan section of my folder

PLEASE USE BLOCK CAPITALS

ALL ABOUT ME

To be completed by parent or guardian.

My vaccination record

Date:	Vaccine:

PLEASE USE BLOCK CAPITALS

ALL ABOUT ME

Date updated: _____ Updated by: _____

My typical day

Time of day:	Description of activty or task:	Comments:

PLEASE USE BLOCK CAPITALS

ALL ABOUT ME

Weight and height tracking record

Date:	Weight (kg):	Height (cm):	Location of weight or height check i.e. hospital, community or home setting:	Weighed or measured by: (parent or healthcare professional)	Signature:

PLEASE USE BLOCK CAPITALS

ALL ABOUT ME

7 MY CARE PLANS

- all care plans
- home / community programmes

My care plans

All my care plans, including home and community programmes.

List of my care plans

Date:	Purpose or type of care plan:	Received from what healthcare professional?	Comments:

List of my home and community programme

Date:	Purpose or type of programme:	Received from what healthcare professional?	Comments:

PLEASE USE BLOCK CAPITALS

8 PEOPLE INVOLVED IN MY CARE

Contact details
for services
and supports

People involved in my care

Please include the names of all healthcare professionals in hospital services.

Contact details for professionals in hospital services

Role / profession:	Name:	Address or location:	Contact details:
Primary Consultant:			
Specialist Consultants:			
Clinical Nurse Specialists (CNS):			

Other healthcare professionals in hospital services

Role:	Name:	Address or location:	Contact details:

PLEASE USE BLOCK CAPITALS

People involved in my care

Please include the names of all healthcare professionals in community services.

Contact details for professionals in community services

Role/profession:	Name:	Address or location:	Contact details:
General Practitioner (GP):			
Public Health Nurse (PHN):			
Pharmacist:			

Other healthcare professionals in community services

Role:	Name:	Address or location:	Contact details:

People involved in my care

Please include voluntary agencies, outreach clinics, family resource centres, school supports etc.

Contact details for other support services and voluntary organisations

Organisation name:	Support provided:	Name of professional:	Contact details:

PLEASE USE BLOCK CAPITALS

9 SPECIFIC INFORMATION ABOUT MY CONDITION

- fact sheets
- leaflets
- guides

10 END OF SHIFT HANDOVER

Summary to be completed by homecare nurses/carers

End of shift handover

Summary to be completed by home care nurses or carers.

Date:	Print name:	Role and organisation:
Time:	Signature:	
Current issues:		
Actions:		
For further information, please consult the nursing or carer patient record.		

Date:	Print name:	Role and organisation:
Time:	Signature:	
Current issues:		
Actions:		
For further information, please consult the nursing or carer patient record.		

Date:	Print name:	Role and organisation:
Time:	Signature:	
Current issues:		
Actions:		
For further information, please consult the nursing or carer patient record.		

PLEASE USE BLOCK CAPITALS

11 REPORTS/ LETTERS/ ASSESSMENTS

12 EQUIPMENT

- home
- school
- medical equipment

Equipment I use at home

Parent or Guardian: Please keep equipment user manuals or equipment instructions in this section.

Type of equipment:	Date of assessment:	Date of receipt:	Review / service due date:	Ordered by:	Comments:

PLEASE USE BLOCK CAPITALS

Equipment I use at school

Parent or Guardian: Please feel free to share this with your child's school.

Type of equipment:	Date of assessment:	Date of receipt:	Review / service due date:	Ordered by:	Comments:

PLEASE USE BLOCK CAPITALS

Special medical equipment

Parent or Guardian: Is there a priority electrical re-connection and / or generator in place?

Device:	Reference number:	Supplier:	Service due:	Link person and department:	Phone:

PLEASE USE BLOCK CAPITALS

13 MY APPOINTMENTS

- diary of appointments
- questions to ask/concerns

My appointments

This may help keep track of all your appointments.

Date:	Time:	What healthcare professional?	Reason for appointment:	Outcome or change to medication:

PLEASE USE BLOCK CAPITALS

Questions to ask or concerns

Write down any questions or concerns you would like addressed by a healthcare professional at visits or clinic appointments.

Date:	State question or concern:

PLEASE USE BLOCK CAPITALS

14 SIGNATURE BANK

Signature bank

To be completed by healthcare professionals.

Date:	Print Name:	Profession:	Organisation:	Signature:

PLEASE USE BLOCK CAPITALS


15

These are your important documents.

You are responsible for this folder and everything inside.

Keep the folder in a safe spot.

Take this folder to all your appointments.