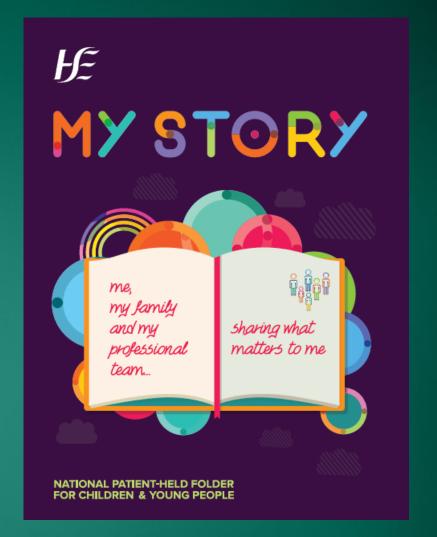


MY STORY

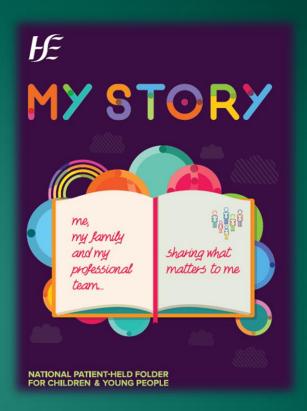
National patient-held folder for children and young people

Information for MY STORY users and issuers, to be read in conjunction with the MY STORY folder





Background and Drivers





The need for change

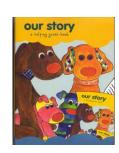


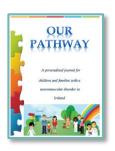
Background: By 2018 multiple patient- held folders were in existence e.g. 2014 Our Story (children with a life limiting condition), 2017 Our Pathway (children with a neuromuscular disorder) and numerous others.

Feedback from families – patient held folders a useful tool, improves communication and care but existing folders could be improved



- Coproduced in an integrated manner, with robust stakeholder engagement including parent representation on the project group
- The project was led by National Primary Care, supported by National Palliative Care, the Integrated Care
 Programme for Children, parent representatives, voluntary organisations and key clinical leaders in CHOs and
 CHI as part of the bespoke MY STORY consultation.
- Project was to design, test and refine the MY STORY folder with three target groups before making it available
 for any service to issue to children and young people who might benefit from a patient-held folder
- HSE Leadership approved the MY STORY PPPG and the PPPG was disseminated nationally in 2022







MY STORY: Design, Refine and Deliver



Project up to 2023 - MY STORY folders were co-designed, tested and refined. The initial target groups were

- · children with a life limiting condition,
- children with complex medical needs and
- children with a neuromuscular disorder

2023 - February 2024

- Training was delivered to lead clinicians in the target groups
- The final MY STORY folder was prepared for dissemination and issued to lead clinicians in the target groups in February 2024
- Lead clinicians in these services will issue the folder and provide guidance to parents and guardians from February 2024
- Information fully available at www.hse.ie/mystory from February 2024, including training presentation
- Any service can now utilise the MY STORY national patient-held folder for their own service
- MY STORY designed specifically to facilitate application nationally



MY STORY: Key Objectives

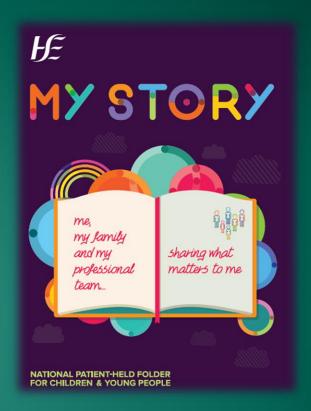


Key Objectives

- Ensure a national standardised patient-held folder is developed to keep all important documents relevant to children
 and young people safely and in one place.
- Support and enable families to actively participate in the coordination of their child's care
- Where developmentally appropriate, ensure that the child or young person has a voice in their own care by completing the "All about ME" section in the MY STORY folder themselves,
- Provide a standard format for sharing the most up to date information related to the child's care from healthcare
 professionals/teams/services for inclusion in the MY STORY patient-held folder
- Ensure guidance for all parents and healthcare professionals to navigate this tool with ease, thus driving integrated child and family centred communication and care



Purpose





MY STORY: Child and Family Centred Coordinated Communication



	M	Y STORY	/
Hello, my name is:)
)
My date of birth is			
	ATTACH PHOTO HERE	7	
		J	
I have an Emergency Care Plan:	Yes O	No O)
I have Allergies	Yes O	No O)
I am Allergic to:)

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





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

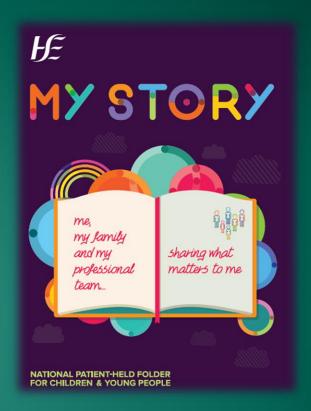
- Review the MY STORY folder to obtain up to date and relevant information related to this child or young person.
- Provide a copy of all specific guidelines/care plans for this child or young person, relevant to your area of care, for inclusion in their folder.
- · Complete the visit/clinic summary 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.



Overview





Overview of MY STORY: 15 sections



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 vist or clinic spopniment by the relevant - healthcare professional - multilosciplany team
Section 5	Medication management - my prescriptions - medication instructions - bod for medication changes
Section 6	All about me - me, my family and what matters to me - my dely 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, leafets 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













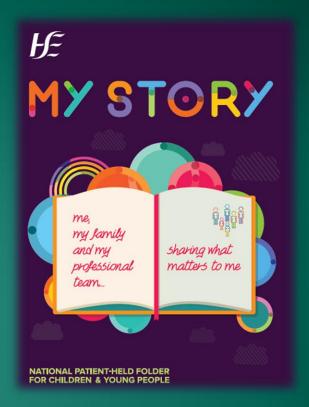








Sections





Section 1: My Personal Details and Emergency Contacts



My personal details and er	nergency contacts				
To be completed by my parent or guardian.					
Child's name:	Date of birth:				
Address:					
	Eircode:				
	terpreter required: es No Language:				
Medical Card: Yes No Lo	ng Term Illness Card: Yes No				
Hospita	al Information				
Hospital name and address: Chart or medical record numb					
Parent/Gua	ardian 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					
	Carer Information				
Significant Carer 1	Carer Information Significant Carer 2				
	_				
Significant Carer 1	Significant Carer 2				
Significant Carer 1 Name:	Significant Carer 2 Name:				
Significant Carer 1 Name: Relationship to child:	Significant Carer 2 Name: Relationship to child:				
Significant Carer 1 Name: Relationship to child: Phone number: Email address:	Significant Carer 2 Name: Relationship to child: Phone number:				

- Key Information about the child and family held in one central location
- Easy to read
- Importance of including significant carer information for some families



Section 2: My Emergency Care Plan



- This section is relevant for those children and young people who have an Emergency Care Plan
- The child or young person's Emergency Care Plan/Ambulance Care Directive is filed in this section, located at the front of the folder and easy to access in an emergency situation
- Standardised, nationally agreed documents, now in use in all paediatric and neonatal units and recognised by national ambulance services



Section 3: My Recent Medical History



Summary of my medical histor To be completed by my consultant or GP ti Child's name: Chart or medical record number: Allergles: Primary diagnosis: Other medical conditions: Current treatments and medication: Please detail any recent changes to care plan or medication: S.P. Name: glock CAPITALS	al history
Chart or medical record number: Allergies: Primary diagnosis: Other medical conditions: Current treatments and medication: Please detail any recent changes to care plan or medication: G.P. Name: BLOCK CAPITALS	
Allergies: Primary diagnosis: Other medical conditions: Current treatments and medication: Please detail any recent changes to care plan or medication: G.P. Name (BLOCK CAPITALS)	Date of birth:
Primary diagnosis: Other medical conditions: Current treatments and medication: Please detail any recent changes to care plan or medication: G.P. Name: BLOCK CAPITALS	Gender: M F
Other medical conditions: Current treatments and medication: Please detail any recent changes to care plan or medication: G.P. Name: BLOCK CAPITALS	
medical conditions: Current treatments and medication: Please detail any recent changes to care plan or medication: G.P. Name: BLOCK CAPITALS	
Please detail any recent changes to care plan or medication: G.P. Name: BLOCK CAPITALS	
any recent changes to care plan or medication: G.P. Name: (BLOCK CAPITALS)	
Consultant Signature:	Date:
PLEASE USE	E BLOCK CAPITALS

- Ideally completed when the child or young person starts using the folder
- Can be completed by primary paediatrician or specialist consultant
- Can also be completed by the family GP



Section 4: Healthcare Professional Visit / Clinic Summary



Healthcare pro	fessional visit or clini	c summary		
	d after each visit or clinic appointme care professional or multidisciplinar			
Child's name:		Date of birth:		
Chart or medical record nu	umber:	Date of visit or clinic appointment:		
Type of visit or clinic appoi	intment:			
Healthcare professionals p	oresent:			
Current Issues:				
Summary of healthcare professional assessment:				
Recommendations and follow up actions:				
Medication changes:				
Healthcare	Name: (BLOCK CAPITALS)			
professional:	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			

- Completed by the healthcare professional at each clinic appointment or professional visit to the home
- Short summary of professional assessment, recommendations/medication changes, outcomes and follow up plan
- Useful communication tool for sharing outcomes of professional reviews with the family and multidisciplinary team
- Additional sheets can be printed in colour from the webpage on A4



Section 5: Medication Management



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)

- Log applies to medication changes, as advised by clinicians to parents/guardians in the clinic setting or over the phone
- Changes recorded in a standard format and easy to read
- Additional sheets can be printed in colour from the webpage on A4



Section 6: All About Me



ALL ABOUT ME





The voice of the child/young person is central to MY STORY.....

sharing what matters to me

- Sheet 1: Family photo and introduction to the family
- Sheet 2: Other important relationships and likes/dislikes
- Include child/young person's input if appropriate
- Update as required

ALL ABOUT ME

Othe	r things ti	hat we would like	you to know a	bout our family	
	Other I	mportant people to	o me and to m		
Name:		Relationship:	20	Contact details:	3
		What matte	rs to me		
Things that make me feel good:					86
Activities that I enjoy:					
Things I don't like:					<i>(</i> □ (□))
Other things that matter to me:					
		PLEASE USE BLO	CK CAPITALS		
		-		•	



Section 6: All About Me



ALL ABOUT ME



How I sleep				
I have a good sleep pattern:	Yes No	zzz		
My routine at home:	Day time:	z ^{zz}		
	Night time:	<i>Q</i> *		
What helps me sleep:				
I use a sleep system:	Yes No Type of sleep system:	<u></u>		
I use a special mattress:	Yes No Type of mattress:			
I need to be turned during the night	Yes No How often:			



- By completing each of the relevant sheets, readers have a good sense of the daily life of the child/young person
- Especially useful for hospital admissions, respite stays and to professionals providing home care support
- A final blank page to capture anything else the child/young person feels is important to share through words or art, whatever way they wish to express themselves
- Additional sheets can be printed in colour from the webpage on A4

ALL ABOUT ME







Section 7: My Care Plans



My care plans



All my care plans, including home and community programmes.

	List of	f my care plans	
Date:	Purpose or type of care plan:	Received from what healthcare professional?	Comments:
	List of my home a	nd community pro	gramme
Date:	Purpose or type of programme:	Received from what healthcare professional?	Comments:

- Individual care plans can be filed in this section with a summary of when the care plans are provided and updated
- Care plans come in many different types and formats e.g..
 individual family care & support plan, clinical care plans
- Home and School programmes can also be filed in this section
- Additional sheets can be printed in colour on A4 paper from the webpage



Section 8: People Involved in my Care



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:					
DI FASS LISS DI OCK CADITALS						

- Two sheets: to record contact details of key individuals providing care and support to the family in <u>hospital</u> and <u>community</u>
- Standard format for recording information and easy to read
- Useful to record changes in healthcare professionals working with the family and/or changes in contact details/clinic location
- Third sheet: Contact details of other organisations and support services that the family are linked with

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



Section 9: Specific Information About My Condition



- This section has been designed to include specific information relevant to the child/young person's clinical condition
- Provides a place for patient specific information e.g., fact sheets, condition specific leaflets, guides, relevant support groups and other resources
- Flexible and adaptable for children and young people with a range of conditions and diagnoses



Section 10: End of Shift Handover



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: Signature: Current Issues: Actions For further information, please consult the nursing or carer patient record. PLEASE USE BLOCK CAPITALS

- · A standardised, dated and signed handover at the end of shift.
- Relevant for those who have multiple homecare nursing/carer organisations involved with the family
- Brief update of any new issues or actions. Not intended to be a
 detailed report but a signpost to parents/professionals to review
 relevant professional's records for an update on any changes to
 care routines that may have been required
- To be used by all homecare nurses/carers irrespective of the employer
- Additional sheets can easily be printed in colour on A4 paper from the webpage





- Provides a place for filing most up to date reports, letters and assessments
- Best if filing is chronological, with most up to date documentation at the front of this section
- Easy to find in the MY STORY folder
- Flexible and adaptable for children and young people with a range of conditions and diagnoses



Section 12: 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:

- Three sheets in this section not all sheets are relevant for all children and young people
- First sheet is to record equipment used in the <u>home</u>
- Specific details of each piece of home equipment and due date(s) for review and/or servicing
- Space for details of the healthcare professional who prescribed the equipment
- All sheets in this section can easily be printed in colour on A4 paper from the webpage

PLEASE USE BLOCK CAPITALS



Section 12: Equipment



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:

- Second sheet: record of equipment used in the school setting.
- Also includes due date(s) for review and or servicing and details of healthcare professional who prescribed the equipment
- Third sheet: <u>Special medical equipment</u>, eg. oxygen, suction machines, non invasive ventilation machine
- Includes contact details of supplier/company who provide maintenance and/or breakdown service

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

PLEASE USE BLOCK CAPITAL



Section 13: My Appointments



My appointments



This may help keep track of all your appointments.

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

 Useful to have all appointments recorded in one central place - children & young people attending services have multiple appointments

Sheet 1: to record details of all appointments

 Sheet 2: list of questions or concerns that the young person, parent/guardian wish to ask on the day of the appointment

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

PLEASE USE BLOCK CAPITALS



Section 14: Signature Bank Section 15: Other





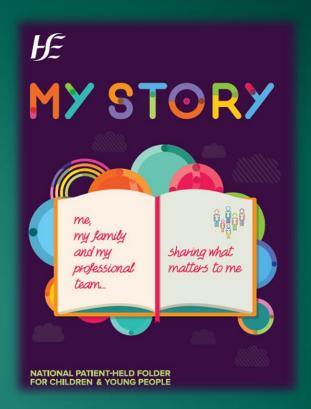
- The Section 14 Signature Bank is a required section for any contributor to the MY STORY folder
- Full name in BLOCK CAPITALS and the signature are recorded and dated



- · Section 15 is blank and untitled
- Useful for other information which the child, young person and their family wish to include in their folder



Where can I find MY STORY?





HSE MY STORY is available online



 our health ser	vice	How can we help	you? Q
<u>Services</u>	<u>Health A to Z</u>	Staff and Careers	About Us

Home > All Health Services > Everyday Care > Primary Care

> Primary Care

- > Enhanced Community Care
- Community Healthcare Networks
- > Enhanced Community Care in Cork Kerry Community. Healthcare
- Chronic disease management programme
- > Lymphoedema
- Community Funded Schemes
- > Building a Better GP and Primary Care Service
- > GP Out of Hours
- > Primary Care Teams
- > Children First
- General Practice Nursing
- > East Coast Area Diabetes
- > National PHN Service
- > Your Good Self

My Story National Patient-Held folder

Purpose of the My Story National Patient-Held folder for Children and Young People

The My Story folder has been created by the HSE for the purpose of promoting child and family centred communication and coordination of care for children and young people with specific healthcare needs. The sections within the folder are to be completed by parents or 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 or 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 or clinic 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 and/or care plans for this young or young person, relevant to your area of care, for inclusion in this 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

The entire HSE MY STORY folder is now available online at www.hse.ie/mystory



HSE MY STORY available online



The entire My Story folder is available to download and print:

For Home and Clinic Printing

These files are for printing the relevant section or page of the My Story folder on a standard home or clinic printer.

The "inside pages" file is useful for quickly locating a specific page you wish to print without having to go through the entire folder.

- > My Story folder full document (home or clinic printing) (PDF, size 2.5 MB, 49 pages)
- > My Story folder inside pages (home or clinic printing) (PDF, size 2 MB, 32 pages)
- > My Story folder exterior cover (home or clinic printing) (PDF, size 351 KB, 3 pages)
- > My Story folder section dividers (home or clinic printing) (PDF, size 447 KB, 32 pages)

For Professional Printing

For services who wish have the HSE My Story national patient-held folder for children and young people commercially professionally printed, the relevant files for the My Story exterior cover, section dividers and inside pages are available here.

- > My Story folder exterior cover (High res for professional printing) (PDF, size 391 KB, 3 pages)
- > My Story folder cover wrap (High res for professional printing) (PDF, size 382 KB, 1 page)
- > My Story folder inside pages (High res for professional printing) (PDF, size 2.1 MB, 32 pages)
- > My Story folder section dividers (High res for professional printing) (PDF, size 516 KB, 32 pages)

The HSE has made these documents available for all services to access and utilise for any children and young people who might benefit from a patient held folder.

Information on how to use the My Story folder is also available here:

> How to Use the HSE My Story national patient-held folder for children and young people

The webpage www.hse.ie/mystory

Divided into three distinct sections:

- 1) For Home and Clinic printing For parents and healthcare professionals
 - 2) For Professional Printing
 For commercial printing of the MY
 STORY folder
- 3) Training on how to use the MY STORY folder



www.hse.ie/mystory

HSE My Story Project Leads:

Irene O'Brien, Clinical Nurse Coordinator, Children with Life Limiting Conditions

Margaret Rafferty, Project Manager Primary Care Services

