

MY STORY



NATIONAL PATIENT-HELD FOLDER FOR CHILDREN & YOUNG PEOPLE



Hello, my name is	::			
I liked to be called	d:			
My date of birth is	5:			
		ATTACH PHOTO HERE		
I have an				
Emergency Care Plan:		Yes	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

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



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 planshome 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



My personal details and emergency contacts



To be completed by my parent or guardian.

Child's name:	Date of birth:
Address:	'
	Eircode:
	Elicode.
Language(s) spoken at home:	erpreter required:
Yes	No Language:
Medical Card: Yes No Long	g Term Illness Card: Yes No
Hospital	information
Hospital name and address:	Chart or medical record number:
Parent/Guar	dian information
Parent/Guardian 1	Parent/Guardian 2
Parent/Guardian 1 Name:	Parent/Guardian 2 Name:
Name:	Name:
Name: Relationship to child:	Name: Relationship to child:
Name: Relationship to child: Are you legal guardian? Yes No	Name: Relationship to child: Are you legal guardian? Yes No
Name: Relationship to child: Are you legal guardian? Yes No Phone number:	Name: Relationship to child: Are you legal guardian? Yes No Phone number:
Name: Relationship to child: Are you legal guardian? Yes No Phone number: Email address:	Name: Relationship to child: Are you legal guardian? Yes No Phone number: Email address:
Name: Relationship to child: Are you legal guardian? Yes No Phone number: Email address: Language(s) spoken: Emergency contact: Yes No	Name: Relationship to child: Are you legal guardian? Yes No Phone number: Email address: Language(s) spoken:
Name: Relationship to child: Are you legal guardian? Yes No Phone number: Email address: Language(s) spoken: Emergency contact: Yes No	Name: Relationship to child: Are you legal guardian? Yes No Phone number: Email address: Language(s) spoken: Emergency contact: Yes No
Name: Relationship to child: Are you legal guardian? Yes No Phone number: Email address: Language(s) spoken: Emergency contact: Yes No Significant C	Name: Relationship to child: Are you legal guardian? Yes No Phone number: Email address: Language(s) spoken: Emergency contact: Yes No arer information
Name: Relationship to child: Are you legal guardian? Yes No Phone number: Email address: Language(s) spoken: Emergency contact: Yes No Significant C Significant Carer 1	Name: Relationship to child: Are you legal guardian? Yes No Phone number: Email address: Language(s) spoken: Emergency contact: Yes No arer information Significant Carer 2
Name: Relationship to child: Are you legal guardian? Yes No Phone number: Email address: Language(s) spoken: Emergency contact: Yes No Significant C Significant C	Name: Relationship to child: Are you legal guardian? Yes No Phone number: Email address: Language(s) spoken: Emergency contact: Yes No arer information Significant Carer 2 Name:



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:	М	F
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)			
or Consultant	Signature:	Di	ate:	

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 nu	umber:	Date of visit or clinic appointment:
Type of visit or clinic appoi	intment:	
Healthcare professionals p	present:	
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.



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)





Introducing my family					
Name:		Relationship:	20	Contact details:	B







Other	Other things that we would like you to know about our family				
	Other in	mportant people	to me and to m	y family	
Name:		Relationship:	20	Contact details:	6
		What matt	ers 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:					



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:	Q		
My Vision:	Good Impaired		
Helpful visual aids:	Glasses: Yes No		
My Hearing: Auditory aids used:	Good Impaired Hearing Aid: Yes No		





	How I get my nutrition : Eating / Oral feeding
My mealtime routine at home:	TO4
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



	My food allergies and / or intolerances
I have food allergies and / or intolerances: Details:	Yes No
I use an epipen:	Yes No lf 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 Bed Pan Urine Bottle Catheterisation
I wear nappies:	Day: Yes No 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:	



	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:	Yes No Times I change my clothes: Day Night
Additional information:	
How I look after my teeth:	Oral/dental care instructions:



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:			
l 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	Yes No		
equipment at home or school:	Type:		
	Seating routine:		
Additional information:			

If I need help moving



I may need pain relief medications before lifting or handling Details:	Yes No		0+
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:			$^{\circ}C$
How I react or look when I have a have a high temperature:			<u> 2</u> 5
What medicine works best to get my temperature back to normal: Additional Information:			0+
I can get cold easily:	Yes No		
My feet and hands can feel cool:	Yes No		
Additional information:			



How I sleep			
I have a good sleep pattern:	Yes No	Z ^{Z^Z}	
My routine at home:	Day time:	-,0,-	
	Night time:	Q≉	
What helps me sleep:			
l 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:		





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 BiPAP/CPAP Other:	Suction Machine Cough Assist	Oxygen AIRVO	
Equipment I use when I am unwell:	Nebuliser BiPAP/CPAP Other:	Suction Machine Cough Assist	Oxygen AIRVO	
I have a respiratory care plan:	Yes No	If yes, please see the care plan section of my folder		





To be completed by parent or guardian.

My vaccination record			
Date:	Vaccine:	/	



Date updated:	1			
Hate lindated:		pdated by	٠,٠	
Date updated.		puateu b	٧.	

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



		W	eight and height trac	king 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:







My care plans



All my care plans, including home and community programmes.

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



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:		

People involved in my care



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

Role/profession:	Name:	Address or location:	Contact details:
General Practitioner (GP):			
Public Health Nurse (PHN):			
Pharmacist:			
	Other healthcare pr	ofessionals in community service	s
Role:	Name:	Address or location:	Contact details:

Contact details for professionals in community services

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:

SPECIFIC INFORMATION ABOUT MY CONDITION

- fact sheets
- leaflets
- guides



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:					
F	or further information, please consult the nursing or	carer patient record.			
Date:	Print name:	Role and organisation:			
Time:	Signature:				
Current issues:					
Actions:					
F	or further information, please consult the nursing or	carer natient record			
	or further information, piease consult the narsing of	edici patient record.			
Date:	Print name:	Role and organisation:			
Time:	Signature:				
Current issues:					
Actions:					
For further information, places consult the purchase an extinct recent					
For further information, please consult the nursing or carer patient record.					





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:

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:

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:



- diary of appointmentsquestions 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:

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:



Signature bank



To be completed by healthcare professionals.

Date:	Print Name:	Profession:	Organisation:	Signature:





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.