

The New Purple Folder Health Record for Adults with a Learning Disability in Hertfordshire

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People with a learning disability die an average of around 25 Years younger than the rest of the Population in the UK

[LeDeR 2019]

Delays in Diagnosis is one of the identified reasons for these early deaths.

The new Purple Folder aims to help reduce these delays by:-

Providing health professionals the Information they need to make personalised reasonable adjustments and understand the persons ways of communicating

Provide a clear document to help the person, and those that support them, to be empowered to ask for the reasonable adjustments and communication methods they need, within the legal framework the health profession has a duty to follow.



Hello



Please stick a photograph of the owner of this Purple Folder in this space.

This is really important so health professionals can see what they are like when they are healthy and happy.

I have a video of me on my best day, you can watch this by

Asking me to see it - in my favourite videos in my smart phone

My name is Alfred Smith

The name I like to be called FREDDIE

I use a Health App: Yes / No

Details: I use the NHS App

For those supporting the completion of this Purple Folder:

It is essential that the information in this purple folder is as accurate as possible. Pages must be reviewed every year at the time of the annual health check, the review must be recorded on the sheet in the annual health check section.

The initial Changes



Mental Capacity to understand Data Protection Relating to My Purple Folder

This Purple Folder is a record of the owner's health and, as such, will contain confidential and personal information. It is important that the person who owns it understands this and is supported to maintain and store this folder safely.

If the owner does not have the capacity to understand the information stored and the data protection risks then the people that support them will need to make a best interest decision to hold, maintain and safe keep this folder.

Mental Capacity Assessment

Does the owner have the capacity to understand the following points?

- This folder holds important health information about them, meaning anyone they give this folder can read this information
- It should only be health professionals and the people that support them who read and write in this folder
- The good thing about the folder is it will help health professionals know all the health treatments they are having and will help them know what helps the person to accept health treatment
- If they think some of their health problems are very private and they don't want other health professionals knowing about them, they can ask the health professional NOT to write about it in their folder.

Could the owner understand and remember all this information about the Purple Folder?

Yes / No (please delete as appropriate)

Please detail how they communicated to indicate this in the box below:

If the answer above is no, and they are not likely to be able to gain capacity to understand with more time then the people who support them need to make a Best Interest Decision.

- Does this person's learning disability mean they have barriers to receiving good healthcare?
- Could the Purple Folder help health professionals support the person and reduce the risk of delays in treatment and/or diagnosis? For example, this person may need alternative means of communication, have a reluctance to accept health interventions, difficulties understanding the risks and benefits of investigations/treatments, reasonable adjustment requirements and additional support needs.

If yes, then a Purple Folder will be in their best interest to reduce the known risk of delays in health care diagnosis for people with learning disabilities.

Data Protection

The risks associated with data breach need to be considered and a plan agreed.

1. Where will the file be stored that will mitigate the risk of a data breach?

2. What steps will be taken when going out with the folder to ensure it is kept safely and returned?

3. If a health intervention of a personal/sensitive nature happens, the people who support the person and the health professional involved should discuss whether it is in the person's best interest for this information to be recorded in the Purple Folder (weighing up the element of whether other health professionals would 'need to know'). What has been done to ensure all who may support the owner to health appointments understands this?

Owner's signature (if they have capacity):

Completed by:

Role/relationship to the owner:

Date:

The Purple Folder and this Mental Capacity Assessment should be reviewed annually at the time of the owners Annual Health Check.



The Pages

There are now only eleven core pages

The first 3 Cover Standard Information –

- ▶ name
- ▶ next of kin AND key people
- ▶ Cultural and religious needs
- ▶ Benefits
- ▶ LPA
- ▶ Vaccines
- ▶ Allergies

Plus ...



My vital information for delivering healthcare

I have a learning disability

Name:

Pronouns I like to use (He/She/They): Date of Birth:

Address:

NHS No: Ethnicity:

NI Number: Religion:

Languages I understand (including Makaton):

GP Name and Address:

Next of kin details:

Name:

Is your next of kin actively involved in your life? YES NO

Details:

Other Key Contact Details:

Tel:

Who they are to me:

I give permission for health professionals to talk to these people about me:

YES NO Best Interest consideration Continued Overleaf

Name: I like to be called: Date of birth:

I have an active DNACPR in place. See guide. YES NO

Details:

Spiritual/cultural needs:

I receive Benefits: YES NO

Details:

I believe I am allergic to these drugs:

I believe I am allergic to these foods:

Name: I like to be called: Date of birth:

Lasting power of attorney for health & welfare/personal welfare deputyship

Does anyone have lasting power of attorney/deputyship for your health needs?

Circle or highlight the answer below:

YES NO

If YES store a copy of the lasting power of attorney/deputyship with this document and record here the name & contact details of your attorney/deputy:

Name: Telephone number:

Address:

The nature of my learning disability

Brief overview of your diagnosis and/or how the learning disability impacts you in everyday life. Please highlight any essential information e.g. triggers or indicators that you may become so anxious you could harm yourself or others.

Vaccines

Annual Flu Vaccine dates	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Was Flu given via nasal spray	<input type="checkbox"/> YES <input type="checkbox"/> NO								
Covid-19 Vaccine dates	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Covid-19 Booster Vaccine dates	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
HPV Vaccine dates	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Childhood Vaccines received e.g. Diphtheria, Polio, Measles, Mumps, Rubella etc.	<input type="checkbox"/> YES <input type="checkbox"/> NO								
Pneumococcal Vaccine dates	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Last Tetanus date	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Continued Overleaf





If I am stiff and red in the face – reassure me and give me time to settle into the environment and accept why I am there.

Reasonable Adjustments Equality Act

When you meet me Talk to me first – reassure me that you are someone I can trust and be comfortable with – stroke my hand as you speak THEN talk to my family

Give me time to calm down when I am anxious – talk to me and reassure me that its all OK.

Name	I like to be called	Date of birth:
<p>The reasonable adjustments I need to be help me accept health appointments, investigations, and treatment (in line with the Equality Act 2010)</p> <p>🔗 Think about T.E.A.C.H – Time, Environment, Attitude, Communication and Help – see guidance notes</p>		
<input type="text"/>		
<input type="text"/>		
<input type="text"/>		

If you need to do physical checks ask my family to prepare me for this – they will talk to me to reassure me and use some Makaton and gestures. Please take their lead and use mirror their communication.

If I am anxious, I will rock and groan - give me an update on what is happening and see if I want to go outside while I wait so I can use nature to help me calm.

If I say I don't want you to do something, calmly explain to me what my choices are and make sure I understand **WHY** you need to do it and what the risks are for me if you don't do it.



Communication Accessible Information Standard

1. Identify
2. Record
3. Flag
4. Share
5. Act

Communication sent to me is opened and managed by my parents as I live with and am cared for by them. My sister is also a strong advocate for me and can read my body language communication well.

I make a loud squeal sound when I am excited and I grit my teeth and make a low growl sound when I am unhappy or scared. It is important to acknowledge that you have understood me and can reassure me.

The communication needs I have to be able to accept Health appointments, investigations, and treatment (in line with the **Accessible Information Standard 2016**)

See guidance notes – make sure the GP practice and social care (if involved with you) are aware of these communication requirements and have them flagged on their system.

Make sure someone calls me if I don't follow up, in case I have forgotten what I was meant to do

If I am anxious, ask me about my dog – talking about my dog will help me calm down and then I will be able to listen and accept health treatment

Use Makaton signs for Pain, Its OK [thumbs up] Love, happy, sad and toilet. My family can show you any you don't know.

Send any letters to Janice at Happy Homes as well as to me because if I am scared I sometimes bin letters.



Top Tips to support WITHIN Health Settings



Name	I like to be called	Date of birth:
Top tips on supporting me within health settings Write information that would help someone who had never met you before to know how to help you to make you feel at ease and reduce anxiety if you were in a strange health environment.		
Helping you to understand me 		
Helping me to understand you 		
Eating and Drinking (highlight in capitals and bold any known swallow difficulties) 		
How I use the toilet, wash, and dress 		
Taking medication 		
Name	I like to be called	Date of birth:
Sexual and personal health 		
Moving around and mobility 		
Known barriers, fears, phobias to health investigations and/or treatment and ways to overcome Please use additional pages for specific reasonable adjustments to support blood taking and needle phobias 		
<input type="checkbox"/> I am not happy having blood tests and/or injections, please see 'reluctance to accept blood taking or injections' page for information on how to support me.		
Any other equipment I need and what they are used for Include information about hearing aids, dentures, glasses etc and any top tips on how to help me use them 		

Eating and Drinking

At home I can eat and drink without any help. If I am unwell and in a strange place I will need reminding to drink more, I will need encouraging at each mealtime about why it is important to eat and someone to check I have eaten and praise me. I will need someone to make sure I eat the meals and don't just eat rubbish snacks.

Helping you to understand me

I am usually someone who smiles and chats and you would not know I had a learning disability. If I am rocking, blinking, looking around, twitchy then I am anxious, so I need reassuring to help me calm

Help me to understand you
speak softly

keep it simple

stroke my hand

give me an aura of you being kind and caring through body language and tone.

Acknowledge you understand my noises and movement



Barriers and fears of Health investigations and ways to overcome them

New experiences and people:

Sit with me

Talk to me and Explain what is happening and what will happen next

use my lava lamp and music app

stroke my hand and use nonverbal communication and voice tone to help me feel safe.

OR

General Health appointment anxiety If I am showing anxious behaviour:

Sit with me

Explain what is happening and what will happen next

Distract me by talking about my dog

If possible, have one person stay with me

Allow me to go outside so I can use breathing and calm myself by looking at nature



Signs of being unwell or in pain

- I become lethargic and sleep a lot [I am generally awake all day]
- I don't make eye contact, am quiet and not moving as much.
- I am less resistant to things happening to me and don't use all my communication methods.

Ask me to show you my *Me on My Best day* video – this is 15 seconds long and will help you see how I am when I am well. It is on my phone. Showing you this, will also help make me calm.

When I am well, I can communicate fully. Most people would not know I have a learning disability. I behave in the same way you would expect any other person to behave. I am fully mobile. I go for long walks and bike rides.

I am generally a very happy, polite and talkative person who can join in any level of conversation.

Meet Keith



Annual Health Check Preparation Form

This form helps to prepare a person with a learning disability to get ready for their Annual Health Check. It is a really important part of the surgery because the information you provide will help us to help you. This is because they may have special changes on you that you haven't reported yourself.

If you are someone who knows the person well and are completing this for them, please include the person's name as much as possible to empower them to be aware of their own health.

When it is complete, please return it to their GP surgery so that the Annual Health Check appointment can be booked.

Name: _____

Address: _____

Name of person helping you and your role: _____

Contact details of that person: _____

Date of last annual health check (if known): _____

Do you have a Purple Folder? Yes No

If Yes, please bring it to your appointment. If No, please call the Purple Folder for Health Assistants which will be given to you on the day your appointment is made.

STAY HEALTHY AT HOME CHECKLIST

Your GP surgery wants you to stay healthy all year round

Please go through this checklist of things you can do to help you stay healthy at home. Keep it safe in the Annual Health Check section of your Purple Folder.

If you cannot download or print these guides... Can you ask a neighbour? Can you go to your local? If not, please contact the Disability Nurses for

Annual Health Check Page

This page is for logging important information about my annual health check which must be updated annually.

Date of last Annual Health Check	Was an Annual Health Check Health Action Plan Given? (Y/N) If no, date followed up with GP	Date Annual Health Check Health Action Plan tasks completed	Date Baseline measurements updated in Purple Folder front section (Y/N)	Date Purple Folder checked and updated following Annual Health Check (All Purple Folder information must be checked and updated annually)	Name and role of person filling in this section

Urine Colour Chart

Are You Drinking Enough?

1 to 3 is normal wee

4 to 8 you must rehydrate!

That means you need to drink more water.

If it doesn't become a better colour then tell someone as you may need to see your doctor.

But Good Collaborative working across 365 days a year, using **Connected Lives Principles** can be the difference Between Avoidable Deaths and early Diagnosis





eQUALITY

for people with learning disabilities

The New Additional Pages

Name

I like to be called

Date of birth:

Additional health conditions/health intervention support

i Health professionals use this page to summarise your specific medical interventions and the reasonable adjustments you use to enable this.

Area of Health: (e.g Epilepsy/Physiotherapy for respiratory/SALT)	
Health professionals involved, names and contact details:	
Start date/timeframe of intervention:	
Current intervention/health plan:	
Medication/medication plan (if applicable):	

Top tips/reasonable adjustments to support the delivery of this plan (for use should a different clinician be required to pick up this role):

i (See guidance, remember to consider all areas of TEACH and whether adding photos will aid someone to support this person in your absence.)



The New Additional Pages



Name	I like to be called	Date of birth:
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Your health plan after today's appointment

Today (date)

I have seen you for

We have agreed:

i (Please write in simple language with clear handwriting and drawings if necessary, what the person needs to do, any medication - the exact details of how to take etc. Before they leave, ask them to repeat the plan to you, ensuring they have understood. If there is doubt about whether they fully understand, establish who supports them, and whether you can contact them.)

-
-
-

This will help you:

i (Please list why this is of benefit to their health in simple language.)

-
-
-

Things to look out for:

i (Please list possible side effects or anything that means they should get urgent help, and what they should do.)

-
-
-

After this, we will:

i (Please write what they need to do if there is a follow up plan or if they are not better following the above.)

-
-
-

i Note to health professional – If you are concerned the person does not have capacity to understand and consent to this plan, then your clinical decision is being made in the person's best interest. For complex decisions, you may choose to link with the key people in the person's life to support you in making this best interest decision.



The New Additional Pages



eQUALITY

for people with learning disabilities

Name

I like to be called

Date of birth:

Reluctance to accept blood taking or injections



Historically, have you had the capacity to understand the reasons bloods need to be taken/injections need to be given, and the risks to your health of not having them?:

i (Please give some examples from the past of the level of understanding you had for the REASONS for a blood test/injection and risks of not having it.)

If you have historically *had capacity* to decide to have blood tests/injections, what were the best ways to support you to have these?:

i (e.g. playing music, distraction, specific venue, specific person, shielding so you can't see, gentle holding or sedation etc)

If historically you *did not have capacity* and a *best interest decision* was made on your behalf with injections/blood tests, what were the least restrictive methods for achieving these?:

i (e.g. playing music, distraction, specific venue, specific person, shielding so you can't see, gentle holding or sedation etc)



Hertfordshire



The New Additional Pages



Name _____ I like to be called _____ Date of birth: _____

Support with helping assess mental capacity for specific health investigations/treatment.

i Remember that it is assumed that all people have capacity to make decisions, but where somebody who has a learning disability who MAY NOT have the capacity to weigh up the risks and benefits for a specific health investigation or treatment and May refuse essential treatment WITHOUT understanding the risks of that decision, then a MENTAL CAPACITY ASSESSMENT SHOULD BE MADE by the HEALTH PROFESSIONAL

If it is safe to delay treatment and allow time to support the person to make an informed decision, then the Health Professional should seek the support of the people who know the person best to take time to communicate with them in the most effective way and environment for that person.

[PLEASE NOTE – This form is NOT for use when there is immediate risk to health. In that circumstance the assessment of capacity will need to happen immediately and where it is agreed that the person does not have capacity to make an informed decision for this investigation / treatment then a Best Interest Decision would be needed immediately]

1. [To be completed by requesting Health Professional] **Medical intervention/treatment required/recommended and DATE:**

2. [To be completed by requesting Health Professional] **Exact questions and answers the health professional will be assessing capacity against:**

- i** e.g. Covid Vaccine – the person will need to understand that 1. Covid is a nasty illness that people can die from. 2. The injection helps reduce chances of being very poorly if I get Covid.
- 3. More people with learning disabilities die from Covid than those without learning disabilities.
- 4. The doctor thinks it is a good idea for me to have the injections.)

Name _____ I like to be called _____ Date of birth: _____

3. [To be completed by requesting health professional] What is the timeframe for the people who know this person well to return this information for the health professional to make the mental capacity assessment?:

4. [To be completed by People who know this person well] Following support to the person Note the ways that the information was communicated, the number of attempts, what the person's responses were and the level of understanding these responses indicate the person had:

i **Medical professional** – the assessment of mental capacity remains a clinical decision, it is your clinical judgement whether the information provided is enough for you to make this assessment or whether you need further face to face to confirm, before moving onto a best interest decision (if they lack capacity).

Safe Handover

Purple Folder Handover Agreement

Where someone does not have capacity to look after their own Purple Folder and keep their personal information safe, then this form can be used as a receipt for those supporting them.

The Purple Folder contains confidential information. Therefore, if lost, this is a breach of GDPR and must be reported and treated in line with Data Protection policies/procedures.

This receipt should be completed whenever the Purple Folder owner is admitted to Hospital or goes to stay in a different home environment, temporarily or permanently, and takes their purple Folder with them.

The person relinquishing the folder should ensure this is completed and keep it as receipt/evidence of the Purple Folder now being the responsibility of a different organisation.

If the person later returns to their home and the Purple Folder is returned, then again this should be completed as receipt of its return.

I,

(name of person who supports the Purple Folder owner and is handing the folder)

State that this Purple Folder, belonging to

(name of the person that the Purple Folder contains the health information of)

has been handed over with the relevant information to

(name of the person receiving the folder)

Job role:

Of establishment/ward

Signed

(person handing over the folder)

Print name:

Role/Relationship to the Purple Folder owner:

Date

Signed

(person receiving the Folder)

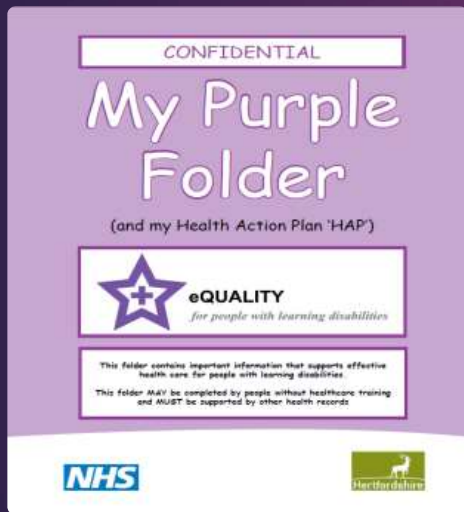
Print name:

Role/Relationship to the Purple Folder owner: ...

Date



The Purple Folder is now in A4 only



The folder will be supplied with the inserts BUT all pages will NOT be included as it was requested that these are available for completing electronically and self printing.

All pages will be available on [My Purple Folder | Hertfordshire County Council](https://www.hertfordshire.gov.uk/services/adult-social-services/disability/learning-disabilities/my-health/my-purple-folder.aspx)
<https://www.hertfordshire.gov.uk/services/adult-social-services/disability/learning-disabilities/my-health/my-purple-folder.aspx>

The NEW Pages will SOON be updated on there. If a person has absolutely no access via friends family or people who support, to complete electronically and self print, then we will print a set of blank pages for hand written completion

The Guide and webinar on how to complete the Purple Folder WILL be made available on the website too



The Purple Card



The Purple Card is available **IN ADDITION** to the Purple Folder for people who are likely to be out and about Independently It is NOT aimed to replicate or replace the Purple Folder, but gives immediate information on reasonable adjustments where someone may not have either their Purple Folder OR a person supporting them in a sudden health change situation





As we have around 4000 Purple Folders in circulation it is a BIG task to get them all replaced !

You can :-

- ▶ *Await dates when we will have open days in Stevenage and Apsley to come and collect the new folders for people you support, bringing their full names and date of birth.*
- ▶ *contact us by email at purplefolder@hertfordshire.gov.uk and state the full name and DOB's of the people who have Purple Folders that you are replacing and we will get in touch to arrange receipt of these*
- ▶ *If you have a Social Worker or Community Learning Disability Nurse due to visit you, you can request that they bring a replacement for you and log this.*
- ▶ *You can email or message to propose another option !*
- ▶ *You can request Purple Cards for people who are independent at the same time*

What Next ?

