A guide on how to support someone with a learning disability to fill in the Purple Folder.

The Purple Folder is available in Hertfordshire for all adults with a Learning Disability. The Folder is provided with dividers. All internal pages can be downloaded, completed electronically, printed and then added to the folder. The pages are on the website If you are unable to print, then a blank copy can be printed for you to complete by hand, contact purplefolder@hertfordshire.gov.uk

The folder is ***not*** written in easy read. This is because the purpose of this folder is to provide health professionals with the essential information, they need, to deliver health care that the person needs.

Use this guide, the example pages and this webinar (https://youtu.be/y3b8NxtsR6c) to help the person you are supporting to make their Purple Folder reflect the help required with meeting their health needs.

Section	Guidance
Sheet inside front cover	**'Mental Capacity to agree to having a Purple Folder' –** this sheet contains an explanation of what to complete and why. Whoever is supporting the person with completing this folder can complete this section.
'Hello' front page divider	It is ***very*** important to have a photo stored here. It is also important for a video of the person on their best day to be stored on either a smartphone or tablet [wherever possible]. This can be shown to the health professional, to help them see what the person is usually like so they can see how far off their baseline they are, giving them an indication of how unwell the person may be. If you are supporting this person to a health setting and ever think a health professional is not recognising the severity of symptoms displayed, you can use these to show the health professional how different the person is. ***Top tip*** *- We have made a video to show examples of what to include in the 'Me on my Best Day' video. You can watch it here. Make sure it is no more than 20 seconds long, showing how the person communicates, moves and their level of independence.*
Section 1: My Vital Information Section	**My Vital Information Section** Most information on this page is self-explanatory. We are going to break down the information that you may need more help with when filling it in. It's written in the first person, as we want to help empower people in having a say and an understanding of their own health needs as much as possible. ~~~~~~~~~~~~~~~~~~~~ **Next of Kin** – please detail how involved the person's next of kin are in their life. It is important to record, in the **Other Key Contacts** section, the details of other people who are involved in this person's life and knows them well. This is so they can also be consulted and considered as someone who would be able to advocate on their behalf in health settings. **Best interest consideration** is where the person cannot communicate themselves that they would want the **Other Key Contact** to be considered as an advocate. So, recording details of why this is the most appropriate person is important. This can then be considered by the health professional as being in the person's best interest. ~~~~~~~~~~~~~~~~~~~~

DNACPR - If the person you support has a Do Not Attempt Resuscitation Document in place from a doctor, it is important that you check this and make sure you question it if you think it may not be correct. We have made a guide to help you.

Guide to DNACPR/Respect for Carers

Easy read information about DNACPR

Benefits – This is handy to have in the folder as some healthcare may be free when you are in receipt of certain benefits, for example, opticians and dentists. If the details of the specific benefits the person receives is in the folder, they can then show this to the service if they are asked about entitlement to free treatment.

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

Once a person reaches the age of 16 years, they become responsible for their own health decisions. If they do not have the ability (capacity) to understand health treatment options, then these decisions will be made for them by the health professional acting in their 'best interest'. They should always consider parental and carer views in this best interest decision, but it is the health professionals' decision.
This is in line with the Mental Capacity Act. For some parents this is extremely challenging and stressful as they can no longer make health decisions for their child unless they have lasting power of attorney (or deputyship if the person lacks mental capacity and is over 18 years) to make health and welfare decisions on behalf of their child.
For more information on lasting power of attorney and deputies, please see the Government website: https://www.gov.uk/make-decisions-for-someone
If someone does have lasting power of attorney/deputyship for the person, it is a good idea to store a copy with these pages so it is instantly accessible should the individual enter a health setting and evidence is needed to prove that the parent can act on their behalf.

The nature of my diagnosis or learning disability

It is important not to over fill this section*.** The more information there is here the less likely it is to be fully read. Display key information in bullet points, which would be relevant to the person, when in a health setting needing treatment or investigations. ***What would that health professional most critically need to know?

Vaccines

It's helpful to know the last Tetanus/Flu/Covid-19 vaccines the person has had. If the person is reluctant to accept injections and finds themselves in a health setting where it may be possible for vaccines to be administered, i.e., if the person is unwell, sedated, or needing a general anaesthetic. Then it can be arranged that these are given opportunistically, under a Mental Capacity and Best Interest Decision whilst its achievable.

Reasonable adjustments I need

It is a legal requirement under **The Equality Act 2010** for health professionals to make **reasonable adjustments** to enable a person to get the same healthcare and outcomes as

anyone else. Think about what the person needs to be able to understand and accept health interventions, ask yourself the following:

Time – is this person more receptive at particular times of day? Do they become anxious if they have to wait, or need more time to get used to an environment or to be able to take in the information/accept interventions?

Environment – Does this person struggle with busy/noisy environments? Would pre-planning to have access to a side room, while they wait, be needed? If the person will not accept being seen in some environments, do they need alternatives considered such as their home, or within the car?

Attitude – This is about ensuring health professionals pursue everything possible to get the equitable outcomes. For example, if someone refuses to be examined or have a blood test – record here what can be done to assess their capacity (ability) to understand what needs to happen, why, and what the risks are to their health if it doesn't happen.
If the person does not understand or doesn't accept investigations, then what is the 'least restrictive' way of achieving these? For example, if it was done at home, covertly or under sedation. Record any tips on how to achieve health interventions in the least restrictive way to help health professionals make these decisions**.**

Communication- Write a bullet point summary of how to immediately communicate with the person in this section. You can expand on this in the communication section below. E.g., Does this person respond well to eye contact and reassuring touch, or is this something that will add to their anxiety? Are there particular behaviour cues or words that communicate the person is happy or distressed?

Help – If they are struggling to accept health interventions, are there particular people who have a positive influence who may be able to support?

Top tip - *Remember to think outside the box when it comes to reasonable adjustments, and make sure that their GP Practice has these recorded and flagged too.*
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Communication needs I have

It is a requirement, under **The Accessible Information Standard** for health and social care professionals to **Ask, Share, Flag, Record** and **Use** a person's preferred means of communication.

Make sure you use this space to expand on the information that you have put in the reasonable adjustments section where you may have already considered communication.

Does this person like to use communication aids such as easy read information, should the health professional use the picture tools at the back of the folder? Highlight this here.
Think about if there are certain phrases that will cause distress or help them relax.
Also think about any top tips, such as:

"*Send health letters to my sister as well as me because I bin scary looking letters*"
"*Please do not touch me to reassure me as I will scream"*
"Talk about trains for a few minutes as this will help me relax and accept health interventions."
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	Add information about sensory needs, such as requiring a hearing loop, braille, or an interpreter.
	Top tips on how to support me with my everyday living needs When completing this section, it's important to consider the differences between the person's abilities when they are well, to when they are unwell. Record here the help the person would need should they be in an unfamiliar place with unfamiliar people around them. For example, if a person can feed themselves, consider the additional steps/prompts needed to enable this if they were in hospital without the usual people who support them available. Consider things like, would they need prompting to pour themselves a glass of water and drink it? If there are critical things that come to mind, you must highlight them here, and remember to highlight if there are additional pages in the folder that the health professional should read in relation to this. Make sure these things stand out – for example, if the person has **swallowing difficulties.** **Sexuality/Personal Health** Consider aspects of the person's life such as masturbation, and whether they would be able to understand the social differences between what they do at home and what is acceptable within a hospital environment. Consider menstrual cycle and whether there are additional cues and tips on how to support the person with this. My body
	Known Barriers and Fears and ways to help overcome them This is where you should share top tips on how to help someone with a known fear, and things that have helped the person in the past so they can have health interventions or treatments. If the fear is around bloods being taken/injections, then make sure you complete the **Reluctance to accept blood taking or injections** page and signpost to this here using the tick box. ~~~~~~~~~~~~~~~~~~~~ **Other equipment I need and what I use it for** Use this section to identify how and when this person uses their equipment, especially if it is slightly different to the way someone may expect. For example, if the person has a walking frame and likes to hold the handle when sitting in bed and moving it away would cause distress.
	My signs of being unwell or in pain Record in the first box what the person is like when they are well, including how to access their **'Me on My Best Day'** video or pictures. The second box is to record how someone may be when they are unwell or in pain, **keep this section brief but clear**. This section is critical for ensuring health professionals don't assume the way someone is presenting is because of their learning disability. This also empowers people who are supporting this person to indicate to the health professional how different they are when they are well. Often someone with a learning disability will have alternative ways of communicating ill health or pain. Health professionals may not recognise this, resulting in delays in diagnosis

	or treatment. For example, someone who laughs as a sign of extreme pain. Use your knowledge of the person and record information about occasions where they have been unwell or in pain and how they communicated this through their behaviours, actions, and words. ~~~~~~~~~~~~~~~~~~~ **Summary of long-term health conditions** Here is where you record a quick overview of any known conditions to help a health professional look holistically at the person and the current health condition they are presenting with. E.g., Cerebral Palsy, Encephalitis, Epilepsy etc. Not all systems within the health service automatically inform each other, so don't assume the health professional will immediately have prior knowledge of these conditions. If there is a health professional currently involved relating to a condition, record here ***'see health professionals involved section'*** and detail their involvement in that section. ~~~~~~~~~~~~~~~~~~~ **Long-term medication I take** Make a note of ***long-term medications*** that the person takes here. Do not keep a record of medication that regularly changes as this could change and mean it is open to error. Keep a separate record of current medication and always take this along with the Purple Folder to health appointments.
	Baseline Measurements This is for keeping an annual record of height, weight, BMI Blood Pressure etc. These measurements can help identify changes early, that could mean the person has an undiagnosed illness. It is best to complete this at annual health check time. Any other measurement record charts used more regularly, should be kept separately but taken along with the purple folder to health appointments. ~~~~~~~~~~~~~~~~~~~ **If I became very unwell suddenly** Think about how scary/distressing this may be for the person, and what things in their life would help them at this time. Think what sounds, smells and items could provide comfort, even if the person does not appear aware of their surroundings. Think about where they would choose to be cared for if they could decide and are at end-of-life care. You should also consider downloading the What If document. If you think about the question *'would you be surprised if this person died in the next year'* and the answer is *No, you wouldn't be surprised,* then it is important to discuss with the person's GP whether they should be considered for **Advance Care Planning**. This is something that will then be discussed as a multi-disciplinary decision. If it is agreed to complete advance care planning, then the palliative care team can support the family/paid carers to develop this. This Advance Care plan should be stored in the Purple Folder. There are different versions, but Hertfordshire County Council uses one called a 'Respect' document. **Health professionals involved** For the health professional to build a full picture of what is needed, and who is involved in the person's life, use this space to record details of all professionals who have been and are currently involved. For every health professional currently involved, a separate

	Additional Health Intervention/health condition sheet should be completed and signposted to in this section, so the health professional knows to read it. ~~~~~~~~~~~~~~~~~~~ **Additional people involved in my health and wellbeing** To provide holistic care, it is good to have a holistic insight into the persons world and who is in it to help them. This area is for recording information on professionals such as social workers and anyone else (friend or a service) who play a significant role in the person's life.
Section 2: Annual Health Check Section	**Annual Health Check Section** Annual health checks are offered by GPs to all people on their Learning Disability register from the age of 14 years. For more information click here Before attending an annual health check, it is good to complete Annual Health Check Preparation Form and use this to ensure the time at the appointment is used to cover the main areas of concern you identify. Provide a copy to the GP and store a copy in this Annual Health Check section. An annual health check is once a year and looking after health is 365 days a year. Here is a link to the Stay Healthy At Home Checklist of things you can look out for all year round to avoid delays in diagnosis. Store a copy in **this section** and tick the ones that are in place in the person's life. After an Annual Health Check, the person will get a **Health Check Action Plan.** This should be stored in the plastic wallet here, and make sure the actions are carried out. Anyone who supports the person should use Annual Health Check time to make sure the Purple Folder is reviewed and up to date, do this with the person and complete the Annual health Check chart page accordingly.
Section 3: Health Appointment Record Section	**Health Appointment Record Section** **No one other than a health professional should write in this section.** The health professional should be asked to write a **very brief synopsis** of the appointment and actions. This is **not** a record of the full details of the appointment for carers or the people who support this person. The purpose of this section is as an aide to health professionals to make well-informed diagnostic decisions, it shows health professionals an overview of all health interventions the person may be receiving or has received prior to seeing them. Make sure these pages are kept in chronological order. If the person needs information written down to help them understand, remember what has happened, and what will happen next, or so they can show someone who supports them to help them follow the doctor's advice, they can ask the health professional to complete the page called **Your Health Plan after Todays appointment.** The blank ones of these should be kept in the plastic wallet in this section ready for use. Once they are written up, store in the current conditions and interventions section.
Section 4: Overview of Current Conditions and	**Overview of Current Conditions and Interventions Section** In this section you can complete and store the following pages:

Interventions Section	• **Additional Health Conditions / health intervention support** One of these should be completed for every current area of health work that the person has going on, so health professionals can see what other health professionals are involved (written on page 7) and what their care plan is. **Once no longer relevant, move these pages to the 'this year's health letters and forms'** section at the back of the folder. • **Your Health Plan after today's appointment** As mentioned in the health record section, store here any current **Your Health Plan After Today's appointment** sheets. **Once no longer relevant, move these pages to the archive section at the back of the folder.** • **Reluctance to blood taking / injections** This sheet is to help reduce the risk of delays to having an intervention involving a needle, due to capacity and best interest decisions. By having evidence of the persons general known understanding of the risks of refusing a blood test and information about how these have been achieved safely and with minimal distress in the past (these are called the 'least restrictive' approaches), you can support the health professional to plan the reasonable adjustments and best approaches to use. **Remember** - the doctor who has given the blood form has decided it's in the persons best interest to have the blood test. It is the person doing the blood test, and the people supporting who decide the least restrictive ways of this happening safely and with as minimal distress as possible. **Once no longer relevant, move these pages to the archive section at the back of the folder.** ~~~~~~~~~~~~~~~~~~~ **Other page options** • **Dementia checklist** Once someone is diagnosed with dementia it is important to help prolong their ability to be as independent as possible for as long as possible. This checklist should be used to help change the approach to the care and support they have, to help reduce the impact of their memory changes. **Stay healthy at Home Checklist** As mentioned in the Annual Health Check Section, if you have not been given this in your Annual Health Check, please make sure you have downloaded the relevant tools and helped embed the use of these in the person you support's, everyday life.
Section 5: This Year's Health Letters and Forms	**This Year's Health Letters and Forms** Store here any documents that are no longer relevant from the current conditions and interventions section, health forms/letters and discharge summaries. When you update the Purple Folder annually, **remove these from the folder** and store appropriately and safely elsewhere in accordance with your systems so the Purple Folder remains current and isn't overloaded.

Section 6: Additional Useful Blank Forms Section	**Additional Useful Blank Forms Section** These are additional forms you and health professionals can use. **1. Support with assessing capacity** If the person needs a health treatment or intervention, then ***the doctor*** needs to check if the person has capacity to understand what they need and why they need it. The amount of time spent trying to help the person understand so they can make an informed decision, will depend on their level of learning disability and how urgently the intervention/treatment is needed. If there is no risk in delaying the intervention/treatment, it may mean the doctor has time to ask people who know the person well, to use their expertise in communicating with the person to help them understand. You can use this form to ask for clear directions from the doctor on **what** they want the person to understand and **when** they want this done by. You then return to the doctor, having carried out these actions, for them to assess whether the person does have capacity to make an informed decision about the treatment/intervention. **2. Checklist for appointments –** this is a prompt sheet that you can use to support the person to ensure they are prepared for the health appointment and have everything they may need. **3. Handover sheet for purple folder data protection accountability –** this is for use when the person is going to stay in a different environment. This is to ensure that there is an acknowledgement that the place they are staying now has responsibility for the safe keeping and use of the Purple Folder whilst the person is under their care.
Communication Tools to help make Reasonable Adjustment section	This has useful pictures that may help the health professional to communicate with the person around their health. Make sure these are pointed out to the health professional and use these pictures at home to help the person feel familiar with them and what they mean.

PLEASE ENSURE THAT ALL PAGES HAVE THE PERSONS NAME AT THE TOP TO SAFEGAURD THAT IT IS THE CORRECT INFORMATION FOR THAT NAMED PERSON.

A good Purple Folder can help reduce delays in health treatment and diagnosis and save lives, if you need any additional guidance or support with filling in the Purple Folder, please contact us:

Health Liaison Team **01438 845372**
PurpleFolder@hertfordshire.gov.uk