

## Mental Capacity to understand Data Protection Relating to the 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?** (please delete as appropriate)

**Yes / No**

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

Yes, Fred was able to tell me that this is a really important book and he must keep it safe because if he loses it someone can find it and read all about him and use his information in a bad way.  
Fred will keep his Purple Folder in his bedroom and when he takes it to appointments he will carry it in his bag so he cant lose it.

**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

# 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.

## My vital information for delivering healthcare

### I have a learning disability

Name:	Alfred Smith	Known as:	Freddie or Fred
Pronouns I like to use (He/She/They):	He/him	Date of Birth:	20.1.90
Address:	22 castle Street Watford WD123DW		
NHS No:	12345678	Ethnicity:	White British
NI Number:	NR123456C	Religion:	
What Languages I understand (including Makaton):	I only speak English but get better understanding if things are also written, drawn or explained using gestures at same time.		
GP Name and Address:	Dr Jones – Brilliant Surgery Watford		
Next of kin details:	Mrs Smith – Freds wife	Tel:	01926 2345667
Is your next of kin actively involved in your life? <b>Yes / No</b>			
<b>details</b> My wife Julie is actively involved but she too has a learning disability so would need extra support too.			
Other Key Contact Details:	Janice Jones Happy Homes Support Care worker	Tel:	12345678 – Janice 123465656 – Happy Homes Office
Who they are to me:	My key worker from care provider – Happy Homes Support		
I give permission for health professionals to talk to these people about me	YES / <del>NO</del> / Best Interest Consideration		
Details	I give permission to talk to Janice or someone else from the agency who can help my wife Julie understand what is happening		
I have an active DNACPR in place <b>See guide</b>	<del>YES</del> /NO		
Spiritual/cultural needs:	I am not religious but I believe in all things natural and like wellbeing activities to help me feel peaceful – like being thankful for weather and nature		
I receive benefits:	Yes / No		
Details:			

I believe I am allergic to these drugs:	None
I believe I am allergic to these foods:	Peanuts – I haven't had since I was a child because they made me swell up

## 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:	
Address:	
Tele- phone number:	

## The nature of my learning disability

**i** 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

I have global developmental delay. I attended a special school because I couldn't cope in mainstream schools. I did not get any qualifications. I live with my wife who also has a learning disability. We get help once a week with managing bills, reading our letters and making sure we are looking after our flat. I can do things like wash, dress cook and clean but I get VERY anxious about new things or when things don't happen as they should.

Hospitals and health appointments are a trigger because they are new things. I get anxious and this can make it appear I am cross but it means I am scared. I don't listen well when I am anxious so need things written down so I can get help at home to understand when I am calm.

## Vaccines

Annual Flu Vaccine dates	11.12.2018	14.9.2019	20.11.2020	10.10.2021		
Was Flu given via nasal spray (Yes/No)	NO – I had injection					

Covid-19 Vaccine dates	10.2.2021	14.6.2021
Covid-19 Booster Vaccine dates	16.11.2021	
HPV Vaccine dates	Not had	
Childhood Vaccines received e.g., Diphtheria, Polio, Measles, Mumps, Rubella etc	Yes / <del>No</del>	
Pneumococcal Vaccine dates	Not had	
Last Tetanus date	March 2018	

**The reasonable adjustments I need** to be help me accept health appointments, investigations, and treatment (in line with the **Equality Act 2010**)



Think about **T.E.A.C.H** – Time, Environment, Attitude, Communication and Help – see guidance notes

<ul style="list-style-type: none"> <li>Give me time to calm down when I am anxious – talk to me and reassure me that its all OK.</li> </ul>
<ul style="list-style-type: none"> <li>Write down what was talked about and what I need to do so I can get someone at home to help me do what I need to do. I wont remember what was said</li> </ul>
<ul style="list-style-type: none"> <li>If I am anxious 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.</li> </ul>
<ul style="list-style-type: none"> <li>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.</li> </ul>
<ul style="list-style-type: none"> <li></li> </ul>

**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

<ul style="list-style-type: none"> <li>Send any letters to Janice at happy Homes as well as to me because if I am scared I sometimes bin letters.</li> </ul>
<ul style="list-style-type: none"> <li>Make sure someone calls me if I don't follow up incase I have forgotten what I was meant to do</li> </ul>
<ul style="list-style-type: none"> <li>Always write down what we have agreed so I can show someone – use the 'what we have agreed sheets' at the back of his folder</li> </ul>

- Speak in simple sentences and check back that I have understood by getting me to tell you what we have discussed. Otherwise I will just agree with you but may not have understood.
- If I am anxious ask me about my dog – talking about my dog will help me calm and then I will be able to listen and accept health treatment

## 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 –

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

### Helping me to understand you

Write it down

Use short sentences

If im anxious I cant listen so help me calm first so I can listen

### Eating and Drinking (highlight in **capitals and bold** any known swallow difficulties)

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.

### How I use the toilet, wash, and dress

I can do all this at home. But I may not be brave enough to ask someone where the bathroom is. I will need help remembering how to lock the door, turn on the light, run the tap etc because it will be different to home. I get worried I will pull the wrong switch and make alarms go off, so I may avoid going to the loo or shower because of this worry. If I am in bed I will need regular reassuring about how to call for help if I need the loo.

### Taking medication

Tell me what pills I am taking and why and I can swallow the pills. If I don't understand and you walk away I might not take them.

If its an injection or taking bloods I can get very scared – take time to explain why it is needed and what the risk is to my health if you don't. see barriers fears and phobia page

### Sexual and personal health

I would not need help with anything in this area. I understand what I can and cant do it a hospital setting and would not need any reminding of this.

### Moving around and mobility

When I am well I have no problems moving. I may chose to not move though so I will need reminding to get up and walk around to help me get better. I wont do this unless someone encourages me to.

## 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

### Needle Phobia

- Always explain why it is needed and what it will do to help me with my health.
- Take time to calmly explain because if I feel someone is getting annoyed with me I will not accept anything.
- Make sure I don't see the needle.
- When you are ready ask me if I am ready, chat about my dog to help me calm – tell me to look away and that it will be really quick.
- Praise me

### General Health appointment anxiety

If I am showing anxious behaviours –

- 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

## 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

I don't have any extra aids



## My signs of being unwell or in pain



What I am like when I am well (this is how I behave, communicate, and move). If you have a 'Me on my Best Day' video please make a note here

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 not unwell. It is on my phone. Showing you this will also help 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.



What I am like when I am unwell or in pain (this is how I behave, communicate, and move):

When I am unwell or in pain I become distracted and can't concentrate properly. I can become grumpy and I am not usually grumpy at all. I can snap at people and I would never usually snap

I become very sweaty and I talk in single words rather than my usual full chats.

## Summary of any long-term conditions that I have

I have a history of Depression  
I have a history of chronic constipation

## Summary of any long-term medication that I take

Fybogel for constipation  
Citalopram for depression

## My baseline health measurements



This information is to be updated annually with the Annual Health Check. Please use additional recording pages if these are being measured more frequently (i.e., weight management)

Date	1/11/2020	1.11.2022				
Weight	19 stone 10	17 stone 4				
BMI	41.7	36.7				
classification	Obese III	Obese II				
Blood pressure	135/90	128/85				
Pulse	70	70				
Oxygen Saturation	98	99				
Respiration	16	16				
Height	5ft 8	5 ft 8				

## If I were to become very unwell suddenly, these are the things I need



See guidance notes to see who may also require additional information

I would need a picture of my wife and dog. I would need my ipad and headphones and play Bob Dylan music I would like my crystal stones to help me feel calm. I would like my wife and dog to be with me. I like people sitting with me and talking to me about everyday things.

☐

**I have an advanced care plan**

See guidance to establish who should have an advanced care plan.

## Health Professionals Involved relating to my health conditions (historically or currently)

Name and role: Joe Bloggs – psychologist	Contact details: email JBD@Wellbeing. Telephone 122334748559
Nature of involvement	Wellbeing Service support with CBT
Date involved from/until	Feb 2019 – Aug 2021

Name and role:	Contact details:
Nature of involvement	
Date involved from/until	

Name and role:	Contact details:
Nature of involvement	
Date involved from/until	

## Key additional people involved in my health and wellbeing



This is social workers, key care support etc that have not been mentioned on previous page

Name and role: Arjun Patel Social Worker	Contact details: kjdhwa,dhwjk:
<b>What they do to help me:</b> Supported with housing and set up my package of support – 3 hrs a week to help with bills and letters	

Name and role: Jon Hubbard part of jicareprovision association	Contact details: qwjhawlfnwafhwa.kh
<b>What they do to help me:</b> provides my 3 hrs support a week as above	

Name and role:	Contact details:
<b>What they do to help me:</b>	

## Health Appointment Record

To be completed by the health professional on each visit to a GP / Nurse / Hospital / Dentist / Optician

Please provide only basic information to identify the health issue and the health service provided (with the individual's consent). Please avoid recording details of sensitive health information.

If any information changes do not cross out or erase. Complete a new sheet and store the old one securely.

Date	Name of Health Professional	Profession	Contact Details	Reason for Appointment and Outcome	Signature
20.10.21	Dr Dodd	GP	practice name and town and number	Throat infection – prescribed antibiotics	

## 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 a Health Action Plan Given? (Y/N) If no, date followed up with GP.	Date Health Action Plan tasks completed	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
10/05/2021	Yes	16/09/2021	Yes	12/05/2021	Jon Hubbard – Support worker to Freddie

## Additional health

## conditions/health intervention support



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

<b>Area of Health:</b> (e.g Epilepsy/Physiotherapy for respiratory/SALT)	wellbeing CBT
<b>Health professionals involved, names and contact details:</b>	Joe Bloggs JB@Wellbeing. Telephone 122334748559
<b>Start date/timeframe of intervention:</b>	Feb 2019 – Aug 2021
<b>Current intervention/health plan:</b>	<p>Freddie underwent 12 sessions and has requested I note on here the strategies he is now using and indicators he may need additional support.</p> <p>Fred using breathing exercises to address early stage anxiety. If Fred becomes disengaged, distracted, frustrated in any social or medical situation he would like people to say – remember Fred ... what's the worst that can happen? And 'Do you need to do your breathing?'</p> <p>This will help him steer himself to being grounded again.</p> <p>If this becomes more frequent than once a week and is not successfully enabling him to get past the anxiety, then please rerefer so we can do a fresher session with him</p>
<b>Medication/medication plan (if applicable):</b>	none required

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



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

Time – give Fred Time and make it clear he can take as long as he needs  
Environment – allow him space to go outside to do the breathing exercises

## 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.)

I hate blood tests and injections and if I am asked I will instinctively say NO BUT if you reassure me that you are NOT going to make me have it I will be able to calm... you can then take time to explain to me what it is for and the risks to my health are if I don't have it I can go outside to calm and think this through.  
Then check that I have understood by asking me to tell you back

Make sure you explain in simple language so I understand  
eg one nurse said that she couldn't look up on google 'what is wrong in Freds body - so a blood test is like google.. it can find answers and then make sure I get the right treatment.

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)

- Make sure I don't see the needle.
- When you are ready ask me if I am ready, chat about my dog to help me calm - tell me to look away and that it will be really quick.
- Praise me

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)

I have capacity to understand but I need you to make sure I understand WHY it is needed as I can say NO, but am actually only saying no to the needle and have not listened to the reason I need the needle.

# Your health plan after today's appointment

Today (date) 20.10.21 I have seen you for a throat infection



We have agreed:



(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.)

- You will collect the antibiotic pills from the chemist
- You will take one before breakfast and one before tea everyday
- Even if you feel better you will take them until they have all gone. 7 days
- If you are in pain you can take paracetamol too. You can have paracetamol 4 times a day [2 tablets at a time]

This will help you:



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

- This will get rid of the throat infection
- It may take a few days to start to feel better –
- .
- .

Things to look out for:



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

- If you get a skin rash call the surgery
- .
- .

After this, we will:



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

- Feel better – if you do not then book another appointment
- .
- .



**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**