

EXAMPLE COMPLETED PURPLE FOLDER 2 - AMBA

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:

Amba has a life long severe learning disability. We showed her the Purple Folder and told her what it is about but she has never had the capacity to engage with books of any description and therefore her level of understanding of data protection relation to the Purple Folder is unlikely to be achieved.

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?

Stored in the family home in Dads office cupboard

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

Always carried by parents or sister who will have responsibility for maintaining its safe keeping

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?

Amba's parents and sister are very aware of the risks and would advocate effectively for Amba in such circumstances

Owner's signature (if they have capacity):

Completed by:

mrs and Mrs Khatri and Aanya Khatri

Role/relationship to the owner:

Amba's Parents and sister

Date:

2.12. 21

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 to see this on my ipad or my Mum, Dad or sister's phones

My name is Amba Khatri

The name I like to be called Amba

I use a Health App: ~~Yes~~/ No

Details:

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:	Amba Khatri	Known as:	Amba
Pronouns I like to use (He/She/They):	She/ her	Date of Birth:	20.1.94
Address:	28 castle Street Watford WD123DW		
NHS No:	12345678	Ethnicity:	Indian
NI Number:	NR123456C	Religion:	Hindu
What Languages I understand (including Makaton):	My family speak to me in English mainly but also Hindi with the extended family. My sister uses some Makaton with me too. [see communication section]		
GP Name and Address:	Dr Jones – Brilliant Surgery Watford		
Next of kin details:	Mr and Mrs Khatri	Tel:	01926 2345667
Is your next of kin actively involved in your life? Yes / No			
Details – Amba lives with her parents and her elder sister lives in the same street so also supports with Ambas care			
Other Key Contact Details:	Aanya Khatri 21 Castle Street Watford	Tel:	12345678 Email aanyakhatri@hotmail.com
Who they are to me: I give permission for health professionals to talk to these people about me Detail	My sister – she plays an active role in my life YES / NO / Best interest consideration Although I do not have the capacity to consent to information sharing with my sister, she is someone who knows me well and can advocate my wishes so should be considered to be consulted in my Best Interest. Next of Kin is in agreement		
I have an active DNACPR in place See guide	YES/NO		
Spiritual/cultural needs:	I am Hindu and have always been supported to pray twice a day, I like to hold my holy book and prayer beads. This is part of my daily routine and gives me comfort		
I receive benefits:	Yes / No		
Details:			

I believe I am allergic to these drugs:	None
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I believe I am allergic to these foods:

None – but must not eat beef products

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:	
Telephone number:	

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

Due to a traumatic birth I have cerebral palsy. I am a wheelchair user and need total care. I am non verbal but show my pleasure, happiness, pain and frustration through my facial expressions and body movement.
If someone I don't know approaches and touches me I will indicate fear and dislike of this by tensing up and become red in the face as my breathing is affected.
Always seek advice from my family on what I am communicating and they will help me to calm and accept what is needed.

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 / No					
Pneumococcal Vaccine dates	June 2011					
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"> 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
<ul style="list-style-type: none"> 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.
<ul style="list-style-type: none"> 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.
<ul style="list-style-type: none"> If I need to be lifted out of my wheelchair my dad can do this. Otherwise I need a hoist. Wherever possible I prefer to not be lifted out of my wheelchair except in my own bedroom, so if any physical examinations can be achieved within my wheelchair please do.

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"> Communication sent to me is opened and managed by my parents as I live with them and are cared for by them. My sister is also a strong advocate for me and can read my body language communication well.
<ul style="list-style-type: none"> Stroke my hand and talk in soft tones. It isn't known how much I understand but always tell me what is happening and I do get a lot of reassurance and security from caring tones and reassuring non verbal communication.
<ul style="list-style-type: none"> Use Makaton signs for Pain, Its OK [thumbs up] Love, happy, sad and toilet. My family can show you any you don't know.
<ul style="list-style-type: none"> 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 / scared. It id important to acknowledge that you have understood me and reassure me.

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 quite content – when I am content I rock and smile, when I am excited I rock harder and squeal and when I am anxious or cross I become stiff, hold my breath and go red.

Helping 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 [above]

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

I have swallowing difficulties I have a soft food diet. Pureed to a smooth consistent texture. I open my mouth to indicate when I am ready to eat the next mouthful. My family separate out each element of the meal and talk to me about each spoonful. 'This one has some chicken and some broccoli on it' We have quite a spicy diet so I can find plain food bland and will lock my mouth shut if I don't like it. I like food warm, not cold or hot. I can take a while to swallow each mouthful, so meals take a long time. If I do choke on food my family lean me forward in my chair and pat my back. This has always resolved it to date.

My drinks are from a soft teat tippy cup and I like warm tea with one sugar and I like orange juice. I do not like water or squash so will clamp my mouth shut.

see SALT guide on how to feed me

How I use the toilet, wash, and dress

I wear pads but my family can usually keep me dry by lifting me onto the commode. I usually poo straight after breakfast so become fidgety and this means I want to be put on the commode. I am then put on the commode for wees after lunch, after tea and before bedtime and this means I am usually dry. If I do become fidgety ask if I need the toilet and use the Makaton sign – I will usually then stop fidgeting and my family think this is because I have been understood and helped to not wet my pad.

If I do wet my pad I will become stiff and red faced – my angry communication. When changing my pad play Abba on my iPad – I love Abba and it helps me relax. I have only ever had personal care met by women [my mother and sister] please do not use male staff as I am likely to find this very distressing

I need total care with dressing and again use music, kindness and communicate what you are doing to help put me at ease. Women only to support and with privacy
I have always dressed in traditional Hindu attire so where a Salwar Kameez [loose long top and hareem style pants] It would be unfamiliar and therefore distressing to wear different clothing and would breach my cultural needs.

Taking medication

All medication needs to be liquid and given via a syringe. Tell me I am having medication and show me the syringe and I will usually open my mouth [the only time I don't is if I don't trust you because you are not communicating caring kindness through your tone and non verbal behaviour]

Sexual and personal health

Menstruation is managed via my incontinence pad. I have never shown signs of period pains but I do find a messy pad upsetting so may indicate through stiff body and red face that I am unhappy and want my pad changing

Moving around and mobility

I am at risk of pressure sores and although my wheelchair is my favourite place I do need time on my bed, using a pressure sore reduction mattress. When I am on my bed use my lava lamp App and music on my iPad. Put a cushion behind my back to keep me on a side and swap sides often.

see Physio guide on how to move me

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

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.

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

Moulded wheelchair

Specialist mattress

bed sides

Hoist

commode

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 to watch 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 iPad and on my mum, dad and sisters phones.

I am awake all day, I make happy noises and move a lot. I make eye contact and I show when I am unhappy through stiffening up and changing my noises



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

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

Summary of any long-term conditions that I have

Cerebral Palsy

Summary of any long-term medication that I take

Fybogel for constipation

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	01/11/2020	1.11.22				
Weight	5 stone 10	5 stone 4				
BMI BMI classification	14.6 underweight	14.4 underweight				
Blood pressure	120/70	128/75				
Pulse	70	70				
Oxygen Saturation	98	99				
Respiration	16	16				
Height	approx. 5ft 2	5 ft 2				

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 my ipad and use my lava lamp App. I would need my family with me to comfort me and understand my communication.
I would want my holy book and prayer beads and my family to be able to maintain my prayers twice a day as this is familiar and gives me comfort.
I would want my yellow blanket from my bed and my Winnie the pooh teddy



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: Helena Green Physiotherapist – HPFT		Contact details XXXXX number and email
Nature of involvement	provided postural and exercise guidance for me – see intervention sheet at back of folder	
Date involved from/until	Feb 2019 – current day	

Name and role: Speech and Language Therapist – Dave Smith HPFT		Contact details: XXXXX number and email
Nature of involvement	Swallow assessment and diet advice – see intervention sheet	
Date involved from/until	jan 2020 – March 2021	

Name and role:		Contact details:
Nature of involvement		

Date involved from/until	
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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: XXX email / phone address kjdhwa,dhwjk:
What they do to help me: Supported with carer assessment and getting OT assessment	

Name and role: OT - HCC - Harry Styles	Contact details: XXX email / phone address kjdhwa,dhwjk:
What they do to help me: got hoist, shower conversion and commode sorted	

Name and role:	Contact details:
What they do to help me:	

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.

[illegible]

Annual Health Check Page

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

[illegible]

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)	Physiotherapy
Health professionals involved, names and contact details:	Helena Green – HPFT XXX number XXX email XXX etc
Start date/timeframe of intervention:	Feb 2019 – current date
Current intervention/health plan:	Here the phsio would write bullet point summary of the physion / move / handling processes and guidelines
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.)

When Amba becomes distressed about moving she stiffens and holds her breath. Pause, acknowledge that you understand what she is telling you by saying 'its OK – I understand, its horrible being moved isn't it?' then wait a minute. Talk to her and she loves it if you sing 'let it Go' from frozen

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.

Area of Health: (e.g Epilepsy/Physiotherapy for respiratory/SALT)	SALT
Health professionals involved, names and contact details:	Dave Smith XXX email XXX telephone etc
Start date/timeframe of intervention:	Jan 2020 – March 2021
Current intervention/health plan:	Here they would bullet point summaries what the guidance is re feeding
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):



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

When Amba is not wanting to eat she will clamp her mouth shut. This may be because the food is too cold or bland she like warm spicy food. In order to maintain her weight, find an alternative that she will like.

If she sense you are rushed she will stop accepting new mouthfuls as she likes to take a long time on each mouthful and hates feeling rushed

Talk and stroke my hand to help her feel relaxed and not rushed

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.

Area of Health: (e.g Epilepsy/Physiotherapy for respiratory/SALT)	specialist Dentist
Health professionals involved, names and contact details:	Francis Drake XXX number XXX email XXX etc
Start date/timeframe of intervention:	June 2021
Current intervention/health plan:	write in bullet points the guidance given re teeth brushing and dental care
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):



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

When Amba arrives we all greeted with stroking her hand and smiling as we said hi. This made her smile and relax.
We played Frozen 'let it go' and all sang along
Amba's sister reminded her that it's just dentist look 'AAARH' and showed her about opening her mouth.
Dental examination done in Amba's wheelchair.
Stopped after every second tooth and sang a bit more and chatted, then sister said again 'dentist look - AAARH' and she opened her mouth again

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



It is assumed that all people have capacity to make decisions, but where somebody who has a learning disability does not have the capacity to weigh up the risks and benefits for a health investigation or treatment, it is important to act in their best interest. If the risks of delaying health interventions are high, you may consider it to be in the person's best interests to proceed immediately in the least restrictive way. If it is safe to delay treatment and allow time to try and enable the person to understand and make an informed decision, then the clinician can seek support from the people who know the person well.

Clinician to complete points 1-3 and seek support from people who know the person well to communicate this information and feedback to you for your clinical decision. They can record this under point 4.

Medical intervention/treatment required/recommended and DATE:

June 2021

Dental treatment – need to do an examination of Ambas teeth as there are indications she may have an severe dental issues

2. Exact questions and answers the health professional will be assessing capacity against:



(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.)

- Need to check teeth by looking in moth and prodding the teeth to see if they are OK
- If we don't you could have bad teeth and this can cause you a lot of pain if we don't sort it
- Bad teeth can also cause you to get very poorly with heart and chest and throat problems,, these can be VERY severe illnesses that we don't want you to get.
- First visit we will only look and this will not hurt

3. 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?:

Please let us know within the week as we don't want to leave it if she has abscesses that will get worse if left untreated

4. People who know this person well to note the ways they communicated this information, number of attempts and what the person's responses were:

As her sister, I have spent time with Amba, playing dentists and asking her to open her mouth and say AAARRH. I have used facial expressions to show how if the dentist doesn't look in the OWWW will get worse.

I have used pictures and symbols to show Amba that the first visit is just to look and poke and NOT do anything more.

When I now ask Amba to open her mouth for the dentist and I open my mouth, she does the same. I believe she understands that the dentist means she opens her mouth and it is to check if she has a big OWW that needs fixing.

With support from me, I think she now has capacity and is accepting of the initial investigation. She may become distressed during the appointment but I will be able to remind her of the importance and see if she is happy to proceed at that point.

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).

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.)

Prior to blood tests or Vaccines Amba is told that she needs it so the Doctors can 'stop her feeling poorly' It isn't clear her level of understanding of this, but she does appear to understand that it is necessary but shows that she doesn't like it.

Therefore the blood tests and injections are given based on the fact that they have been medically requested and it is in her best interest, to reduce risk of illness or delays in diagnosis, to proceed using the adjustments and least restrictive approaches outlined below.

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)

Processes that have previously worked –

- Clinician to greet Amba by gently stroking her hand and saying who they are and asking her how she is, This will help her relax and smile.
- Family and clinician to Keep reminding Amba that it wont take long and its to help 'stop her feeling poorly'

- Do all the prep work out of her sight so it reduces the amount of time she can build anxieties.
- Allow family member to stand to the same side as the bloods / injection is given to block the sight of the needle etc
- Family member will gently hold/stroke her arm to reduce the risk of sudden stiffening due to her cerebral palsy
- Family member will sing and talk to her while the procedure takes place.