TRANSITIONS

Healthcare for adults with cerebral palsy

Health Summary

This health summary belongs to

Before you start:

- Read the whole summary to understand the questions under each section
- Complete the summary over time and in stages
- You might find it helpful to gather the information you need before filling in the summary
- Ask for support to complete the summary, for example from parents and health professionals
- Keep the summary in a safe place
- Consider bringing the summary with you to appointments with new health professionals
- Add to the summary over time so it remains up-to-date.
- It may be helpful to update at key times in your life such as being discharged from a health service, attending a new health service, attending a new education setting or starting a new job

Emergency contact

Name	Name
Relationship	Relationship
Telephone Number	Telephone Number

About me

Date of birth:

Medical card number *(if applicable)*	Medical Card expiry date *(if applicable)*
Health Insurance company *(if applicable)*	Health Insurance Policy number *(if applicable)*
Long-term illness Number *(if applicable)*	Drug Payment Scheme Number *(if applicable)*

If you have difficulty with communication, please describe how best people should communicate with you and things that professionals can do to make it easier to communicate such as speaking slowly. If you use a communication system, it may help to attach a photograph of it and how it should be positioned.

If you need support to make decisions, please describe how you are supported

About me

I live *Please tick ✓ the appropriate box*

☐ alone
☐ with parent(s)
☐ with other family member(s)
☐ with friend(s)
☐ Other

You can add more details here

I am *Please tick ✓ the appropriate box*

☐ attending school
☐ attending college
☐ attending a day service programme
☐ attending a training programme
☐ working in a job
☐ looking after family
☐ volunteering
☐ other

You can add more details here

My main occupation is (if applicable)

About my cerebral palsy

My main type of cerebral palsy is

- ☐ Spastic hemiplegia cerebral palsy (also known as spastic unilateral cerebral palsy)
- ☐ Spastic diplegia cerebral palsy (also known as spastic bilateral cerebral palsy)
- ☐ Spastic quadriplegia cerebral palsy (also known as spastic bilateral cerebral palsy)
- ☐ Ataxic cerebral palsy
- ☐ Dystonic cerebral palsy
- ☐ Choreo-athetotic cerebral palsy

You can provide more details or describe how your CP affects you in your own words here

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I was diagnosed with CP at the age of

You can provide details about who diagnosed you and at what hospital/healthcare organisation here

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Gestational age: *I was born at (how many weeks)*

Birth weight: *When I was born, I weighed*

You can provide any other information about your birth and/or your diagnosis here

About my cerebral palsy

Several scales exist to describe how people with cerebral palsy move around, use their hands, communicate, and eat and drink in everyday life. They all use 5 levels and can be completed by people with cerebral palsy or their parent or guardian. These are not tests.

They can be useful for when you're speaking to health professionals about your cerebral palsy.

We have included common scales below if you want to use them.

Gross Motor Function Classification System (GMFCS)

The GMFCS is a widely used method for classifying the movement ability of people with cerebral palsy, with a particular focus on sitting, walking and wheeled mobility.

It emphasises what you usually do at home and in the community.

It is a useful way of describing how you move around.

Read the following and select the one that best represents your movement abilities.

Please tick ✓ the appropriate box

GMFCS Level I ☐	I can walk on my own without using walking aids, and can go up or down stairs without needing to hold the handrail ***and*** walk wherever I want to go (including uneven surfaces, slopes or in crowds) ***and*** can run and jump although my speed, balance, and coordination may be limited
GMFCS Level II ☐	I can walk on my own without using walking aids, but need to hold the handrail when going up or down stairs ***and*** therefore walk in most settings ***and*** often find it difficult to walk on uneven surfaces, slopes or in crowds ***and*** may occasionally prefer to use a walking aid (such as a cane or crutch) or a wheelchair
GMFCS Level III ☐	I can stand on my own and only walk using a walking aid (such as a walker, rollator, crutches, canes, etc.) ***and*** find it difficult to climb stairs, or walk on uneven surfaces without support ***and*** use a variety of means to move around depending on the circumstances ***and*** prefer to use a wheelchair to travel quickly or over longer distances
GMFCS Level IV ☐	I can sit on my own but do not stand or walk without significant support ***and*** therefore always rely on wheelchair when outdoors ***and*** can achieve self-mobility using a powered wheelchair ***and*** can crawl or roll to a limited extent to move around indoors
GMFCS Level V ☐	I have difficulty sitting on my own and controlling my head and body posture in most positions ***and*** have difficulty achieving any voluntary control of movement ***and*** need a specially adapted chair to sit comfortably and be transported anywhere ***and*** have to be lifted or hoisted by another person or special equipment to move

About my cerebral palsy

Add any other information about how you move around here

Manual Ability Classification System (MACS)

The MACS classifies how people with cerebral palsy use their hands to handle objects in daily activities.

It emphasises what you usually do at home and in the community. It classifies your overall ability to handle objects; it doesn't classify the ability to use each hand separately.

It is a useful way of describing how you use your hands to handle objects when talking to health professionals.

You can follow this link to find out more information about the MACS
macs.nu/files/MACS_English_2010.pdf or scan the qr code

Read the following and select the one that best represents **how you handle objects**

Please tick ✓ the appropriate box

☐ **MACS level I**: I handle objects easily and successfully. At most, I have some difficulty performing tasks with my hands that require speed and accuracy, but any difficulty I have doesn't restrict my ability to perform daily activities independently.

☐ **MACS level II:** I handle most objects with some reduced quality and/or speed. I avoid doing some activities with my hands or do them but find it difficult. I find alternative ways to perform daily activities with my hands. Any difficulty I have with handling objects usually doesn't restrict my ability to perform daily activities independently.

☐ **MACS level III:** I handle objects with difficulty and need help to prepare and/or modify activities. I perform activities slowly and sometimes aren't able to do daily activities using my hands. I can perform daily activities independently if they have been set up or adapted for me.

☐ **MACS level IV:** I handle a small number of objects that are easy to manage when the activity has been adapted for me. It takes me a lot of effort to perform activities with my hands and I often can't perform daily activities with my hands. I require continuous support and/or adapted equipment to perform daily activities.

☐ **MACS level V:** I do not handle objects and have very little ability to perform daily activities with my hands. I require assistance to do any activities with my hands.

Add any other information about how you handle objects, your ability to use each hand and which is your dominant hand

Eating and Drinking Ability Classification System (EDACS)

The EDACS classifies how people with cerebral palsy eat and drink everyday.

It is a useful way of describing how safely and efficiently you are able to eat and drink when talking to health professionals.

You can follow this link to find out more information about the EDACS
sussexcommunity.nhs.uk or scan the qr code

Read the following and select the one that best represents **how you eat and drink**

Please tick ✓ the appropriate box

☐ **EDACS level I:** I eat a wide range of different textured foods and drink thin and thick fluids from a range of cups, including through a straw

☐ **EDACS level II:** I take effort to chew, or have mixed or sticky textures. I get tired if food textures are challenging and mealtimes take longer for me than for my peers. I drink thin and thick fluids from most cups

☐ **EDACS level III:** I eat puree and mashed food and I might bite and chew some foods that have a soft texture. I find it challenging to eat large lumps of food and foods that are firm to bite. I drink from an open cup but might use a lid or spout. My ability to eat and drink varies and depends upon how I'm sitting and the support I'm given. I might choose to drink only in certain situations such as with no distractions. I find it challenging to move food from one side of my mouth to the other, to keep food in my mouth, and to bite and chew.

☐ **EDACS level IV:** I eat smooth purees or well mashed food. I find it challenging to eat food that requires chewing. I find it difficult to co-ordinate swallowing and breathing when eating and drinking and need time between mouthfuls to swallow repeatedly. I find it easier to drink thickened fluids than thin fluids, and take thickened fluids slowly and in small quantities. I need support and modifications to my environment to reduce the risk of choking. I find it difficult to control the movement of food and drink in my mouth, to control how I open and close my mouth, and to control swallowing.

☐ **EDACS level V:** I am unable to swallow food or drink safely. I find it difficult to control how I open my mouth and move my tongue

☐ I am tube-fed

Add any other information about how you eat and drink here. It may also be helpful to attach photos of any utensils you use to this summary

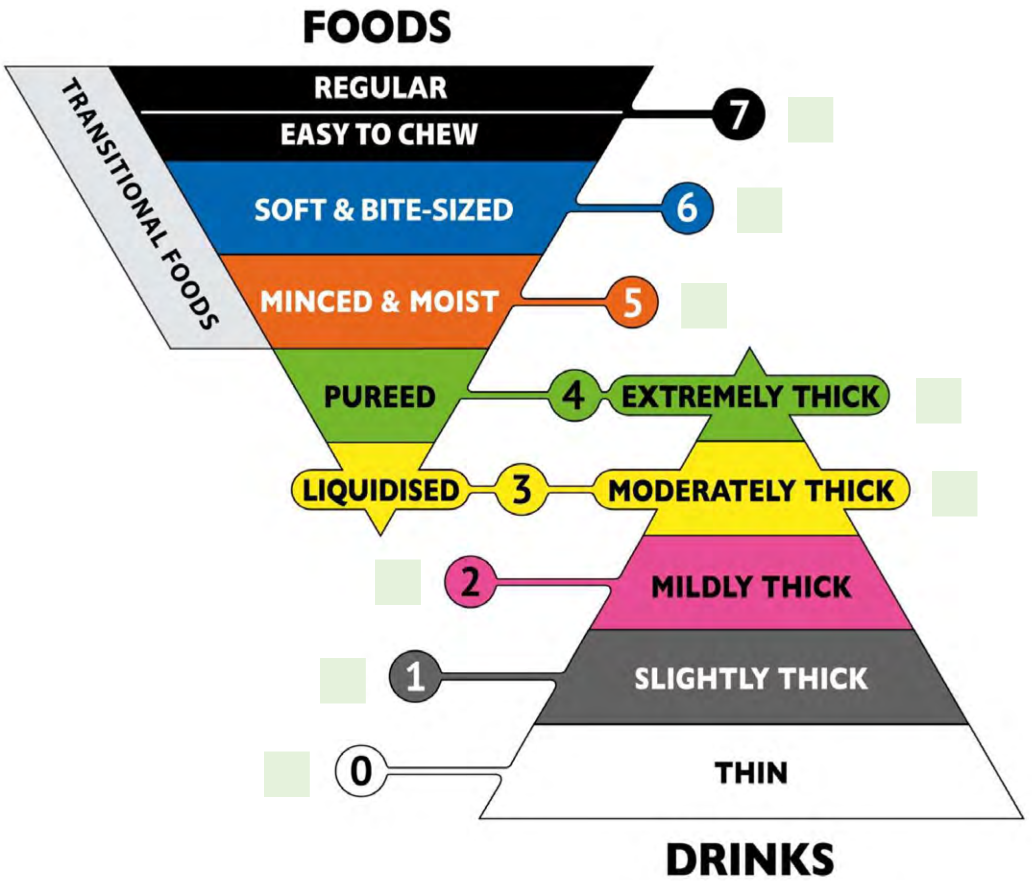
International Dysphagia Diet Standardisation Initiative (IDDSI)

The IDDSI is a standard way of describing texture modified foods and thickened liquids used for individuals with dysphagia

You can follow this link to find out more information about the IDDSI
iddsi.org or scan the qr code

If you have dysphagia, select the levels that you can eat and drink.

Please tick ✓ the appropriate box



Add any other information here

Communication Function Classification System (CFCS)

The CFCS classifies how people with cerebral palsy usually communicate in everyday situations. It is a useful way of describing how you communicate when talking to health professionals.

Communication occurs when a sender transmits a message and a receiver understands the message. All methods of communication performance are considered in determining the CFCS level. These include the use of speech, gestures, behaviours, eye gaze, facial expressions, and augmentative and alternative communication (AAC).

You can follow this link to find out more information about the CFCS
CFCS_English_CP.pdf or scan the qr code

Read the following and select the one that best represents **how you communicate**

Please tick ✓ the appropriate box

☐ **CFCS level I:** I independently alternate between sender and receiver roles with most people in most environments. The communication occurs easily and at a comfortable pace with people I am both familiar and unfamiliar with. Communication misunderstandings are quickly resolved and do not interfere with the overall effectiveness of my communication

☐ **CFCS level II:** I independently alternate between sender and receiver roles with most people in most environments, but the pace of the conversation is slow and this can make it more difficult to communicate. I may need extra time to understand messages, compose messages, and/or resolve misunderstandings. Communication misunderstanding are often resolved and I can eventually communicate effectively with people I am familiar with and unfamiliar with

☐ **CFCS level III:** I alternate between sender and receiver roles with people I am familiar with in most environments. I can usually communicate effectively with people I am familiar with but I can not consistently communicate effectively with people I am unfamiliar with

☐ **CFCS level IV:** I do not consistently alternate sender and receiver roles. I might (a) occasionally be an effective sender and receiver; or (b) be an effective sender but not an effective receiver; or (c) be an effective receiver but not an effective sender. Sometimes I can communicate effectively with people I'm familiar with

☐ **CFCS level V:** I am not an effective sender or receiver. Most people find it difficult to understand my communication. I might have limited understanding of messages from most people. I can rarely communicate effectively even with people I'm familiar with

Add any other information about how you communicate here, including how you say yes/no or indicate that you have understood.

Scoliosis

I have scoliosis *Please tick ✓ the appropriate box*

☐ Yes ☐ No

Describe how your scoliosis is currently and has been managed

Name of doctor or other health professional you see about this and where you see them

Epilepsy

I have epilepsy *Please tick ✓ the appropriate box*

☐ Yes ☐ No

Describe how your epilepsy is currently and has been managed

Name of doctor or other health professional you see about this and where you see them

Fatigue

I currently experience fatigue *Please tick ✓ the appropriate box*

☐ Yes ☐ No

If you see a doctor or other health professional about your fatigue, describe how it is currently managed

Name of doctor or other health professional you see about this and where you see them

Describe any strategies you use to manage your fatigue

Pain

I experience pain *Please tick ✓ the appropriate box*

☐ Yes ☐ No

If yes, where and how much pain did you have during the past 4 weeks *Please tick ✓ all that apply*

	None	Very mild	Mild	Moderate	Severe	Very severe
Head	☐	☐	☐	☐	☐	☐
Neck	☐	☐	☐	☐	☐	☐
Back	☐	☐	☐	☐	☐	☐
Shoulders	☐	☐	☐	☐	☐	☐
Arms, hands	☐	☐	☐	☐	☐	☐
Hips, thighs	☐	☐	☐	☐	☐	☐
Knee	☐	☐	☐	☐	☐	☐
Feet, lower leg	☐	☐	☐	☐	☐	☐
Teeth	☐	☐	☐	☐	☐	☐
Stomach	☐	☐	☐	☐	☐	☐
Skin, pressure	☐	☐	☐	☐	☐	☐
Other	☐	☐	☐	☐	☐	☐

If other, describe where you experience pain

Describe how much your pain affected your normal activities during the past 4 weeks

☐ Not at all ☐ A bit ☐ A lot

Describe how much your pain affected your sleep during the past 4 weeks

☐ Not at all ☐ A bit ☐ A lot

Name of the doctor or other health professional you see about this and where you see them

Describe the strategies you use to manage your pain, e.g. massage, stretching, medication, heat

Other medical conditions

List any other medical conditions you have been diagnosed with, for example, osteoporosis, arthritis, depression, high blood pressure.

Name of condition

Year of diagnosis

Name of doctor or other health professional you see about this and where you see them

Treatment received

Name of condition

Year of diagnosis

Name of doctor or other health professional you see about this and where you see them

Treatment received

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Name of condition

Year of diagnosis

Name of doctor or other health professional you see about this and where you see them

Treatment received

Allergies

List any allergies you have, for example to food or medication

Vaccines

List any vaccines you received as a teenager or adult

Vaccine	Date

Vaccines

List any vaccines you received as a baby or child

Vaccine	Date

Equipment

Select the equipment you use under each category. You can select more than one in each category.

Please tick ✓ all that apply

Mobility

☐ Crutches
☐ Walker
☐ Powered wheelchair
☐ Manual regular wheelchair
☐ Manual specialized wheelchair
☐ Adapted vehicles
☐ Standing frame
☐ Other

You can give more information here including what wheelchair you use and how you drive it

Orthotics

☐ Lower limb orthosis
☐ Orthopaedic footwear
☐ Upper limb orthosis
☐ Upper or lower limb prosthesis
☐ AFOs
☐ Other

You can give more information here

Vision

☐ Special computer equipment
☐ Print display magnification
☐ Magnifier
☐ Audible/tactile devices
☐ Glasses
☐ Other

You can give more information here. You might want to include the level of your visual impairment here.

Equipment

Select the equipment you use under each category. You can select more than one in each category.

Please tick ✓ all that apply

Hearing

- ☐ Hearing aids
- ☐ Alerting devices
- ☐ Personal listening devices
- ☐ Fax or telephone
- ☐ Other

You can give more information here

Communication

- ☐ Communication device
- ☐ Communication board or book
- ☐ Single message switch e.g. Big Mac
- ☐ E-Tran frame
- ☐ Voice amplifier
- ☐ Other

You can give more information here including what system you use and where to find the system if it's not visible.

Daily life

- ☐ Powered beds
- ☐ Powered hoist (with clip)
- ☐ Powered hoist (with loop)
- ☐ Specialised chairs
- ☐ Adapted toilet seat or commode
- ☐ Pressure relieving mattress
- ☐ Shower chair
- ☐ Aids for grasping, holding and reaching
- ☐ Kitchen aids
- ☐ Stair lifts
- ☐ Adapted care
- ☐ Other

You can give more information here

History of orthopaedic surgery

List any orthopaedic surgeries you have received, for example single-event multilevel surgery

Year and age *(e.g., 2015, 10 years)*

Hospital

Type of surgery and reason for surgery

Outcome of the surgery and any complications

Year and age *(e.g., 2015, 10 years)*

Hospital

Type of surgery and reason for surgery

Outcome of the surgery and any complications

Year and age *(e.g., 2015, 10 years)*

Hospital

Type of surgery and reason for surgery

Outcome of the surgery and any complications

History of other surgery

List any other surgeries you have received

Year and age *(e.g., 2015, 10 years)*	Hospital

Type of surgery and reason for surgery

Outcome of the surgery and any complications

Year and age *(e.g., 2015, 10 years)*	Hospital

Type of surgery and reason for surgery

Outcome of the surgery and any complications

Year and age *(e.g., 2015, 10 years)*	Hospital

Type of surgery and reason for surgery

Outcome of the surgery and any complications

History of other hospitalisations

List any other times you have been admitted to hospital

Year and age *(e.g., 2015, 10 years)*

Hospital

Reason

Any complications

Year and age *(e.g., 2015, 10 years)*

Hospital

Reason

Any complications

Year and age *(e.g., 2015, 10 years)*

Hospital

Reason

Any complications

History of other hospitalisations

List any other times you have been admitted to hospital

Year and age *(e.g., 2015, 10 years)*

Hospital

Reason

Any complications

Year and age *(e.g., 2015, 10 years)*

Hospital

Reason

Any complications

Year and age *(e.g., 2015, 10 years)*

Hospital

Reason

Any complications

History of spasticity management (if applicable)

List any other medical or therapy interventions you have received to manage your spasticity, for example Botulinum Toxin or an ITB pump

Year and age *(e.g., 2015, 10 years)*	Hospital or healthcare organisation

Intervention received

Outcome of the intervention and any complications

Year and age *(e.g., 2015, 10 years)*	Hospital or healthcare organisation

Intervention received

Outcome of the intervention and any complications

Year and age *(e.g., 2015, 10 years)*	Hospital or healthcare organisation

Intervention received

Outcome of the intervention and any complications

History of spasticity management (if applicable)

List any medications you use or have used to manage your spasticity

Name of medication	Dose and how often you take/took the medication

Name of doctor and hospital or healthcare organisation that prescribed the medication

Year and age that you started the medication (eg, 2015, 10 years)

When you stopped taking the medication and reason why (if applicable)

Name of medication	Dose and how often you take/took the medication

Name of doctor and hospital or healthcare organisation that prescribed the medication

Year and age that you started the medication (eg, 2015, 10 years)

When you stopped taking the medication and reason why (if applicable)

Name of medication	Dose and how often you take/took the medication

Name of doctor and hospital or healthcare organisation that prescribed the medication

Year and age that you started the medication (eg, 2015, 10 years)

When you stopped taking the medication and reason why (if applicable)

Other medications

List any other medications you take

Name of medication	Dose and how often you take it

Reason for taking it and any other relevant information

Name of medication	Dose and how often you take it

Reason for taking it and any other relevant information

Name of medication	Dose and how often you take it

Reason for taking it and any other relevant information

Name of medication	Dose and how often you take it

Reason for taking it and any other relevant information

Any other medical history

Describe anything else about your medical history that is not captured in earlier sections

Contact details

Contact details for your GP

Name

Phone number

Address

Contact details for your pharmacist

Name

Phone number

Address

Contact details for other health professional

Name

Phone number

Type of professional *(e.g. physiotherapist)*

Address

Contact details for other health professional

Name

Phone number

Type of professional *(e.g. physiotherapist)*

Address

Contact details for other health professional

Name

Phone number

Type of professional *(e.g. physiotherapist)*

Address

TRANSITIONS

Healthcare for adults with cerebral palsy

Additional resources and guides are available on our website

www.cphealthcaretransition.eu ↗

or scan the code

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RCSI UNIVERSITY OF MEDICINE AND HEALTH SCIENCES

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