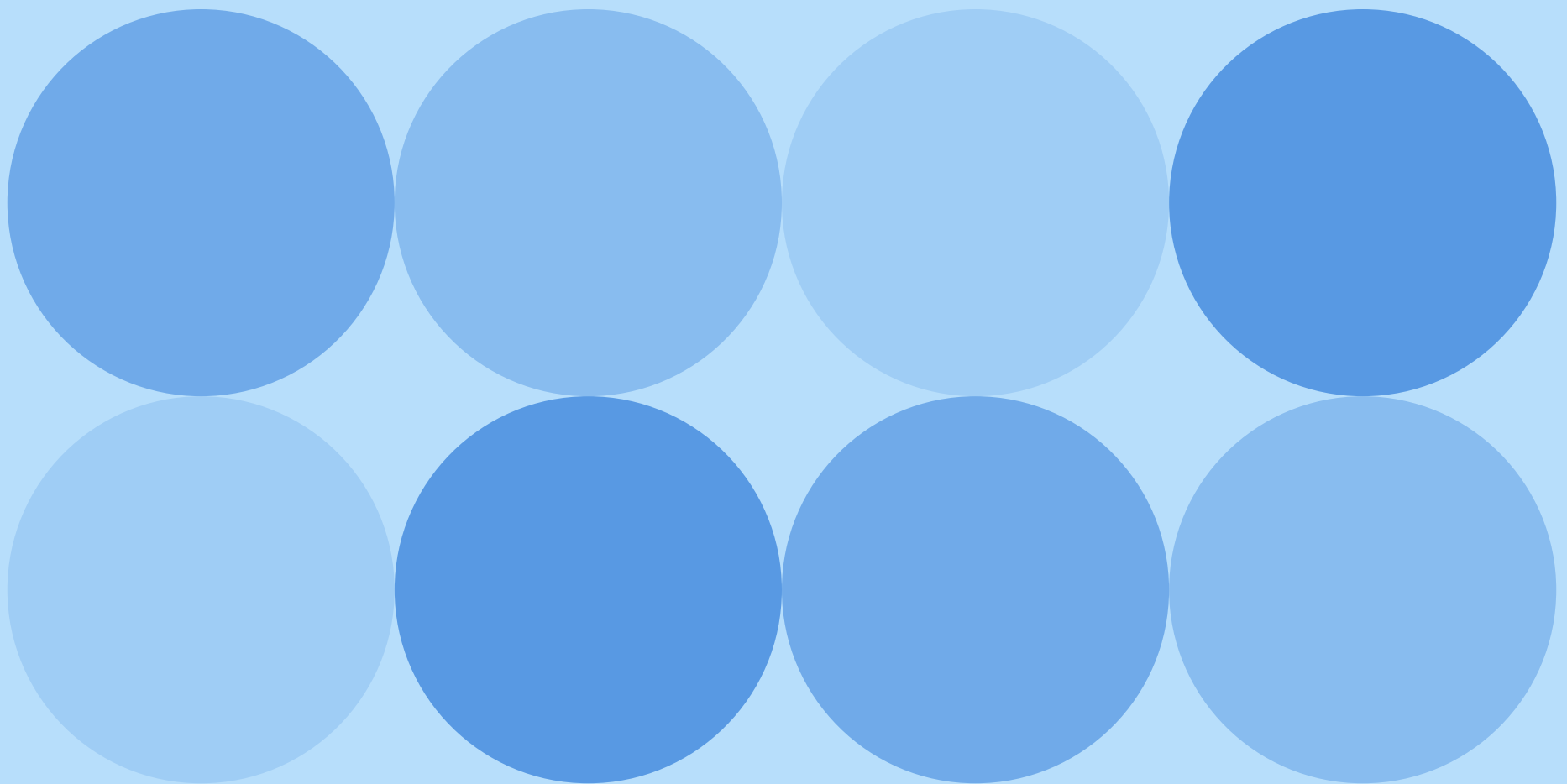


# Your Deep Brain Stimulation Therapy Journey

for Parkinson Disease patients



# A Timeline Overview

Please be aware that appointment times for each stage can vary.

Feel free to ask your clinical team questions throughout your journey.



**Do you have questions?  
Do family & friends have questions?**

Every hospital appointment is an opportunity to ask them.

## You will attend hospital for:



**Consultations** with the multidisciplinary team to discuss next steps.



**Assessment appointment**



**Treatment day (surgery)**



**Initial adjustment or switching on**  
Further adjustments will follow over the course of time.



Assessments >

# Your Hospital Assessments

Feel free to ask how long your stay will be. Bringing someone along who can also speak to your long-term symptoms will be helpful.

Please tell your team early on about any medical conditions and regular medications you take.

Please do not stop taking your medications until instructed by your specialist nurse.

[< Overview](#)

## Past Patient Experience:

Take some food and drink along with you, it may be a long day.

Being off your medication and seen can feel overwhelming. I wish I had practised being off my meds at home first.

Take a list of your symptoms with you so you can give a long term view of how you are, not just in those moments.

## On this day:



You will be examined by the specialist nurse and movement disorder team.



Your movements on and off your medication will be recorded on camera (being filmed is optional; if you consent you will be asked to sign a form).



There will be neuropsychological assessments to test your cognitive abilities.



You will be taken for an MRI scan.

[Treatment >](#)

# Your Treatment Day

Your team wants to support you throughout the day. Always ask if you feel unsure. Always say if you feel concerned about anything.

Your specialist nurse will talk to you about your medication prior to surgery.

[< Assessments](#)

## Tips & Suggestions:

- **Concerned it may be painful?**  
Past patients say they felt no pain during the operation and only experienced a vibration sensation and noise.
- **Concerned about the framing?**  
Past patients liken the anaesthetic injections to a bee sting or dental injection. After the frame is fitted they felt a sense of pressure and heaviness but nothing concerning. You may be left with a headache for a while after the procedure but it will pass.
- **You may want to bring something with you that helps you relax**, like a piece of music, a photo or a stress ball.
- Always **say** if you feel concerned about **anything** or feel discomfort.
- **Once the frame is fitted you can no longer wear glasses**, nurses will help you with moving around throughout the day.
- **The best time to use the toilet is before going into the operating theatre.** Some hospitals will fit you with a catheter if you are asleep throughout.
- **You will be advised when to stop and restart your medication.**
- **The implanted device can feel itchy just after the operation.** This is normal and expected to pass after a few days.



You will be given a theatre gown and surgical stockings to wear.



Your hair will be either partially or fully shaved depending on the centre. Please do not shave your own head prior to surgery.



Different centres perform the framing either asleep or awake, depending on their system and your condition. Please discuss with your surgical team. If awake, after some mild sedation and anaesthetic injections your frame will be fitted.



You will be taken to have a CT or MRI scan.



In the operating theatre you will be covered with drapes. The team will keep you informed of the different phases of the operation if you are awake and will do some simple tests with you to check the positioning and currency of the probe device.



Your friends and family can see you after your operation back on the ward. Most hospital stays will be for around 10 days, during which time there will be further tests to ensure all is well with the device.

[Adjustments >](#)

# Adjustments & Long-term Expectations

Every person's  
experience will  
be somewhat  
different\*.

Throughout your journey  
discuss your expectations  
with your clinical team.

\* Some will see an immediate improvement,  
whilst for others there will be a longer period  
of tweaking before results are seen.

[< Treatment](#)

## Past Patient Experiences:

As soon as I was switched on I felt  
like a totally different person.

I had assumed the effects would be  
immediate, but in reality it's been much  
more of a journey than I had expected.

## Tips & Suggestions:

- Past patients advise keeping your long-term goals in mind and seeing the journey as a continually evolving one.
- **Some may see improvements quicker than others, while others may need more tweaking.** But keeping in mind the abilities you regain can help you balance out any setbacks you may perceive.





**You will be asked to return to hospital to either be 'switched on' and/or adjusted.** Different centres have different timelines, which will be discussed with you. The frequency of adjustments needed over time varies from person to person.



**If fitted with a rechargeable battery you will be taught to recharge your device.** If you don't feel confident, please bring someone with you who can learn how to use the device also. Speak with your team about which device options are available and the pros and cons of each.



**Adjustments:** This part of the DBS journey is best viewed in the long-term. A journal or diary can help you keep track of the progress you are making, even if it feels small or slow at first.

# Need a Mentor?

Would you benefit from hearing a patient's story about their DBS experience?

Speak to your clinical team to put you in touch.

For further community support and connections visit:

**Dystonia**  
UK

Dystonia UK  
89 Albert Embankment  
London SE1 7TP

| 020 7793 3651  
| [info@dystonia.org](mailto:info@dystonia.org)  
| [dystonia.org.uk](http://dystonia.org.uk)

**PARKINSON'S**<sup>UK</sup>

Parkinson's UK  
215 Vauxhall Bridge Road  
London SW1V 1EJ

| 020 7931 8080  
| [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)  
| [parkinsons.org.uk](http://parkinsons.org.uk)

[< Adjustments](#)



Many patients base their decision-making on the lived experience of other patients.

Hearing someone's story can be a source of comfort and clarity.

# Become a Mentor

Interested in  
becoming a mentor  
and sharing your  
experiences with  
another?

Speak to the clinical team  
about volunteering.

For further community support  
and connections visit:

**Dystonia**  
UK

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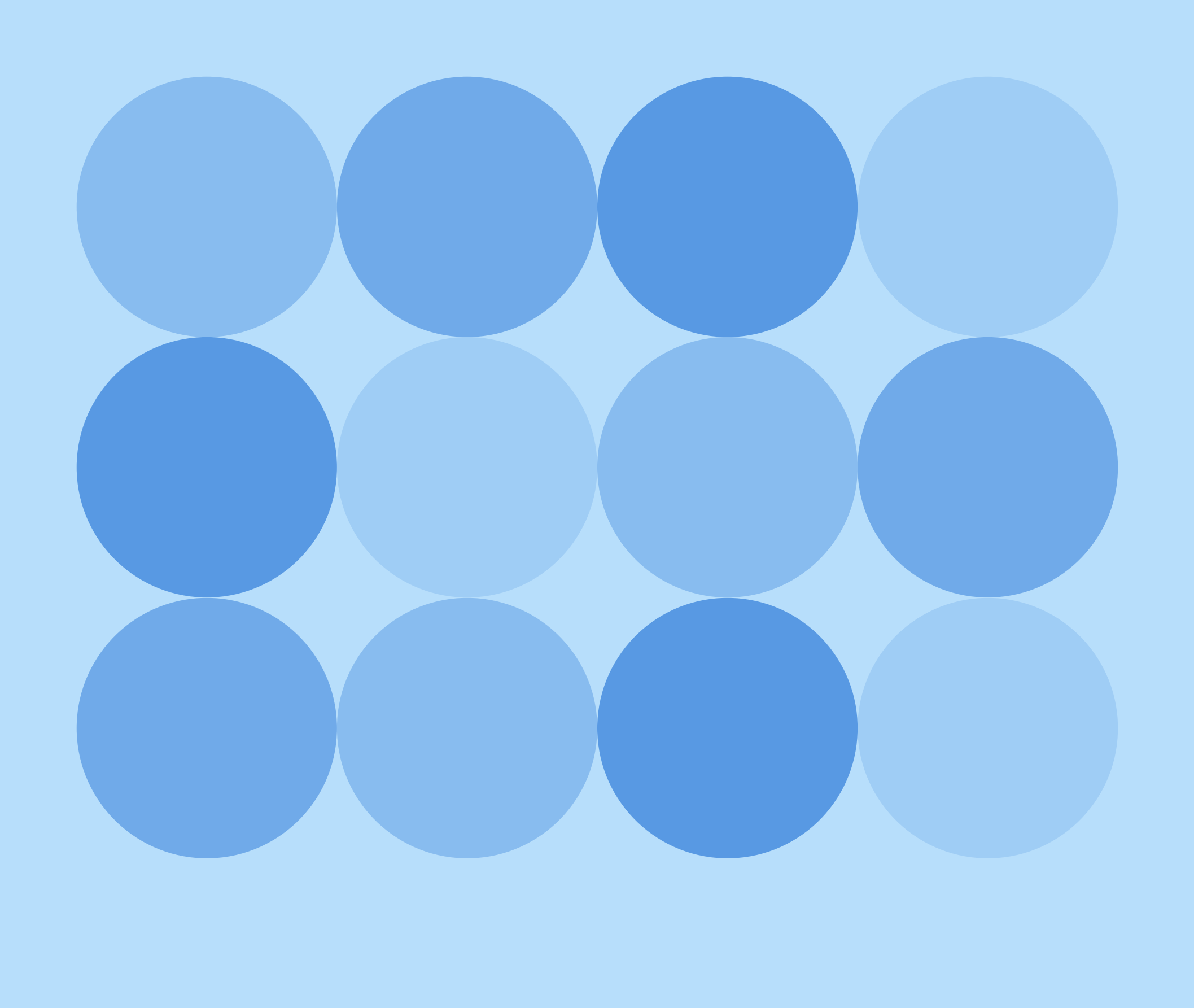
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Are you a patient, carer,  
family member or friend  
of a DBS patient who  
would like to share their  
experience with others?

Sharing your support story  
is invaluable feedback.



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