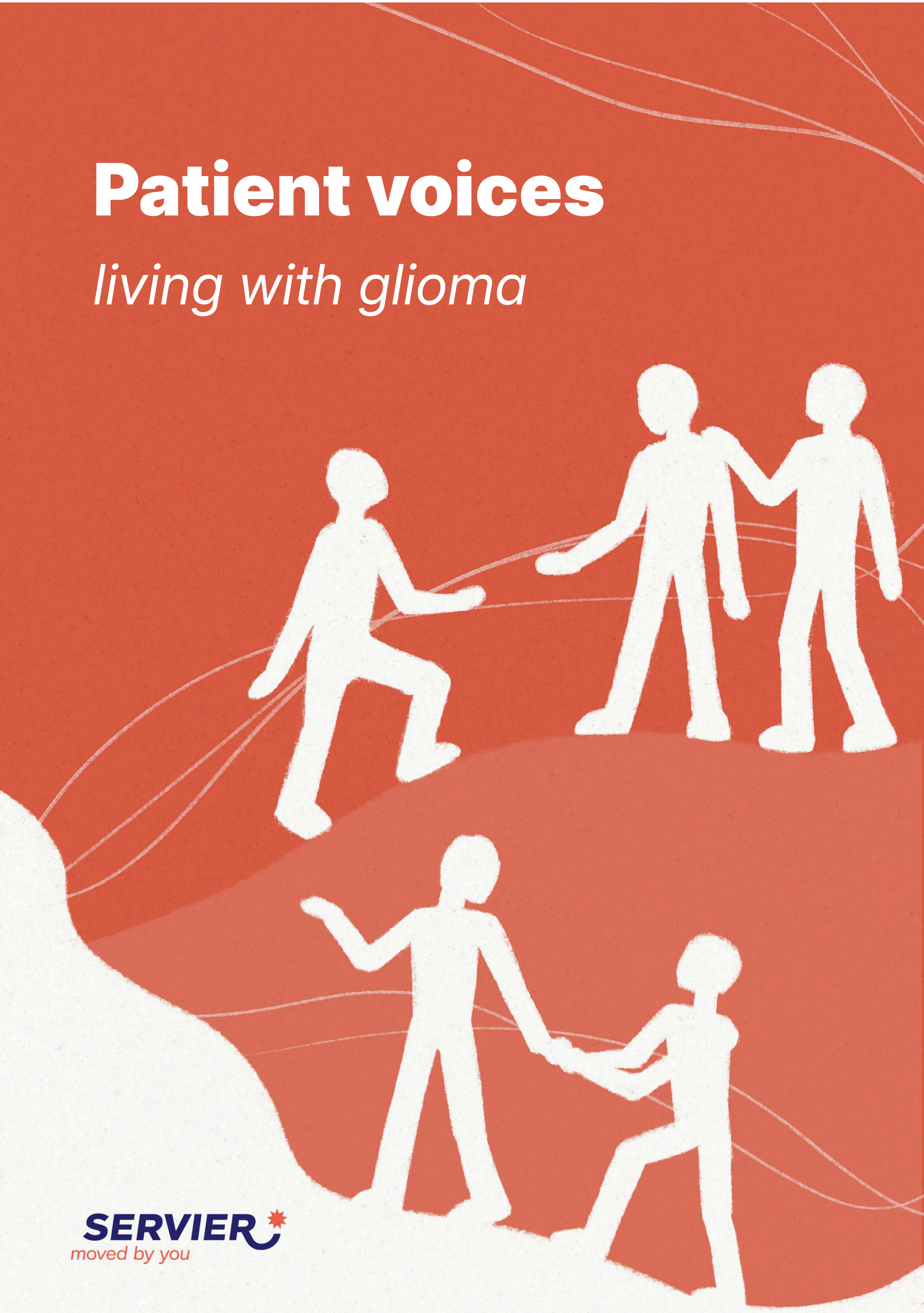
Patient voices

living with glioma



SERVIER
moved by you

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Editorial

When it comes to brain tumors, the spotlight is often on statistics, treatments, and research. However, **behind the numbers are human beings, life stories, and people living with the disease who face a difficult reality and a complex care pathway every day.**

This booklet aims to give them a voice. Patient perspectives must be heard, understood, and acknowledged.

These testimonials are a call to collective awareness. They remind us why research must be supported and strengthened, why raising awareness of the challenges in treating these forms of cancer is vital, and why each of us, in our own way, can and must take action for this cause.

By working together - patients, research teams, medical professionals, companies, and institutions - we can make a difference, accelerate scientific progress, and find new solutions.

This project is proof that we can do things differently, with and for patients, so that their experience becomes a source of strength.

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At Servier, our commitment to oncology is manifested through concrete actions around the globe.

For example, we recently conducted a survey of 120 patients to better understand the issues surrounding biopsies in glioma and to improve our clinical trials. In June 2024, we partnered with AmoyDx to develop an innovative diagnostic test capable of detecting certain mutations in diffuse glioma, enabling us to administer the right treatment to the right patient.

This dynamic collaboration between research, patient associations, the medical community, and innovative companies, which we are proud to promote, is now recognized worldwide. In 2024, for the first time ever, we were voted No. 1 in oncology worldwide according to the PatientView international ranking of the reputation of pharmaceutical companies in the eyes of the patient associations that work with us. This recognition is a testament to the solid partnerships and quality of the relationships we have built in a particularly demanding field, pushing us to go even further in our commitment to them.

The testimonials you will read here are therefore much more than just personal stories; they are pleas to continue working tirelessly together, to create ever more effective treatments, and to promote a better quality of life for all.

I would like to express my heartfelt gratitude to the people who have courageously and wholeheartedly agreed to share their experiences, as well as to the patient associations whose commitment and valuable collaboration make this work possible.

Nicolas Garnier, Chief Patient Officer, Servier

Giving patients a voice

Brain cancer is one of the greatest challenges in oncology. Rare and complex, these types of cancer often affect young adults between the ages of 35 and 45, in the prime of their family and professional lives. One of the most common types, glioma, is known for its slow but unpredictable progression, which disrupts the daily lives of those affected.

The diagnosis often comes as a shock, preceded by inconspicuous symptoms such as headaches, epileptic seizures, or problems with speech and memory. In many cases, the care pathway is a succession of obstacles: delays in treatment, fragmented information, the pressures of medical decisions, and a lack of psychological support. Patients and their loved ones must learn to navigate a sometimes confusing and obscure system, even as their lives are turned upside down.

This booklet was born from a strong belief: behind every medical term lies a life story. These personal testimonials reflect the complexity of the patient journey, with its uncertainties and struggles, but also its hopes. They also highlight the crucial role played by family members, caregivers, and support groups, who are key in providing support.

Giving patients a voice underscores Servier's commitment to going beyond scientific research alone. The objective is to include the voices

of those living with a disease in the very essence of therapeutic solution development. Listening to people's personal testimonials helps us better understand their needs, improve their quality of life and that of their loved ones, and develop a more caring and effective treatment approach.

Throughout these pages, the faces, journeys, and commitments of the individuals are brought to life.

This booklet exemplifies Servier's commitment to not only treating patients but also supporting them, as well as innovating in a way that is always based on the real-life experience of patients.

Servier's patient commitment

Top 10

Servier features in the top 10 of 46 companies ranked by patient associations that work with and/or are familiar with the Servier Group*

140

Patient associations around the world work in collaboration with Servier

1

In just a few years, Servier has risen to No. 1 out of 28 companies in the ranking established by oncology patient associations*

*PatientView Report 2024 survey on the reputation of pharmaceutical companies

More than 70%

Patient opinion included in over 70% of clinical research programs in 2023/2024

100%

All lay summaries are validated by patient representatives and translated into the languages of each country participating in the study

100%

All informed consent forms for participants in Servier Group clinical trials were reviewed by patients in 2023/2024

2 Patient committees created since 2023

Patient Boards: A hands-on role in research

At Servier, including the voice of patients at every stage of the medicine's development cycle is a priority. With this in mind, over two years ago the Group set up “Patient Committees” to ensure that the input of patients and their caregivers is included in the drug development process, as well as in initiatives intended to improve their day-to-day care.

This dynamic began in 2021 with an initial committee of expert patients, which was involved in a wide range of collaborative programs with Servier's R&D teams. The Group now has two international advisory committees; each focused on a specific disease area: cardiovascular and venous diseases, and glioma. Servier also has a specific patient committee in the United States. In the near future, a new international committee will be dedicated to oncology as a whole.

The international advisory committees represent about 10 countries across five continents and provide valuable feedback from patients and caregivers to drive projects aimed at delivering therapeutic solutions that are better suited to their needs and projects that can help improve care.

> **Patient and caregiver expert committees have paved the way for new opportunities to develop increasingly innovative solutions. This kind of collaboration enhances our efforts and is a powerful force for our teams, serving as an everyday reminder of the meaning behind our work. These new collaborative models with patients and their caregivers are essential to making progress in research.**
>
> *Marta Garcia, Chief Patient Officer R&D, Servier*

Spotlight

Patient Committee dedicated to glioma with IDH 1/2 gene mutation

> **This committee has a truly international focus. If we are to address the needs of all patients and their caregivers, it is essential to include voices from all parts of the world in order to develop initiatives that will improve their care and support them in their daily lives.**
>
> *Stéphanie Chatin, Director of Patient Affairs, Servier*

Created in 2024, this committee is made up of a dozen members from around the world, including Europe, Canada, Japan, and Australia.

The goal?

To effectively improve the quality of care for people with this type of glioma and improve their daily lives.

The committee is structured into several working groups, each with specific priorities:

- Raising awareness among healthcare professionals about the needs of patients and caregivers in order to improve care management of this pathology
- Informing patients on IDH mutated diffuse glioma and treatment options, as well as providing patients and their families with appropriate support in their daily lives
- Assisting patient organizations in raising public awareness on the disease burden and the major challenges in treatment
- Ensuring that our R&D projects and clinical trial analysis criteria are aligned with patient expectations

"We are currently working with patient committee members to create a digital guide for patients and caregivers to help them better understand diffuse glioma with IDH1/2 gene mutations, the patient journey, how to manage the condition on a daily basis, and how to be involved in decisions."

John, patient (see testimony p. 20)

Perspectives on glioma

Each story in this booklet reflects the reality experienced by patients and their loved ones when faced with glioma. Behind the statistics and medical protocols lives are turned upside down, daily routines rewritten, and resilience forged in adversity.

By sharing their personal journeys, these women and men provide valuable insight into what it means to live with glioma. Their words shed light on the needs, difficulties, and hopes of patients, and serve as an essential guide for developing therapeutic solutions that are more in line with patients' reality.

These testimonials remind us of the importance of genuine listening. Providing medical care must not be limited to treating a disease, it also involves supporting lives.

" An accidental scan saved my life "

Marcus, patient

Marcus is a 40-year-old Australian who had no symptoms until January 2021, when a seemingly minor accident radically changed the course of his life. That day, he broke his leg in a fall while water skiing. At the hospital, a full scan was performed, as it is the standard procedure in such cases. Healthcare professionals quickly detected a mass in his brain. It was an unexpected but decisive discovery: "Without that scan, I never would have known. That scan saved my life."

An abrupt onset of illness

Apart from his broken leg, which forced him to stay at home, Marcus' priority shifted to his brain. Within three days of the scan, he met with a neurosurgeon in Melbourne. "When he saw me coming in on crutches, he thought I had come to the wrong department!", he jokes. Three months later, he underwent his first surgery, which lasted six hours and removed more than half of the tumor. A second surgery failed due to an epileptic seizure in the operating room. This was followed by 33 sessions of radiotherapy and then chemotherapy, which ended in December 2023.

Daily life turned upside down

Before his illness, Marcus worked almost every day of the week. Now, he can no longer work. The after-effects are severe: dizziness, balance problems, loss of strength on one side.

"I had to relearn how to walk and talk. For the first three months, I could barely speak."

His family became his lifeline.

Throughout his journey, his wife was his constant support, his rock. She asked all the questions, checked every decision, and helped him to feel confident. Marcus learned a major lesson:

"Every patient should have a loved one who can defend their interests."

He laments the use of medical jargon and advocates for systematic psychological support.

Today, Marcus is giving back. Through the Bacchus Marsh Cancer Support Yarning Circle he created, an informal group that gathers occasionally, he allows cancer patients to share

their stories with other people going through the same issues. He got the idea after a trip with the Peace of Mind Foundation, during which he met 32 men in the same situation: "Sharing was a breath of fresh air."

His message is clear: Make more time for personal testimonies and for caregivers.

> **"They need to be better listened to and given more time and space."**

A hoslistic care

Today, the tumor remains stable. His life is shaped by an MRI every six months and a consultation every three months, as well as the ever present "scanner anxiety".

Marcus received excellent care. Apart from his oncologist, he was surrounded by a psychologist, speech therapist, and an occupational therapist, not to mention support from the Australian national disability insurance system.

" People often ask me how my husband is doing, but rarely how I am doing "

Rebecca, caregiver

Rebecca is familiar with the role of caregiver. And for good reason: she often sees them at the Peace of Mind Foundation, the brain tumor patient association she founded in 2013. In 2020, following her husband's relapse, she became a caregiver, taking care of him, who has glioma.

Back in 2007, a little more than 12 years before they met, Rebecca's husband Matt received his diagnosis. He learned the news in the hospital parking lot after a CT scan: he had grade 2 oligodendroglioma, a rare and complex form of brain tumor that mainly affects adults. This was followed by years of treatment including chemotherapy, awake craniotomy, and radiotherapy. In addition, he was actively monitored by the medical teams, with whom Rebecca now also maintains a close relationship, as she is fully involved in decisions, which is rare.

Unfortunately, he suffered a relapse in 2020, shortly after his marriage to Rebecca. This marked a turning point in their life together.

"I was already aware of the situation through my involvement with the association, so I knew this could happen. But you never really understand the impact until you are confronted with it directly", says Rebecca about her role as a caregiver.

Fortunately, she can count on her friends and family and on a “navigator,” a resource person provided by the nonprofit:

"It's a real blessing, because most caregivers are on their own with very little information and use search engines as their only resource".

"The treatment caused more damage than the tumor itself: memory loss, difficulty speaking, weakness on the right side. Nevertheless, we had no choice but to deal with it", explains Rebecca.

Caregiving: A full-time commitment

Being a caregiver is a full-time job. Every day, she has to manage the entire household on her own. Shopping, managing finances, medical appointments, coordinating assistance: her professional life was significantly affected by her caregiving responsibilities at home, and as her husband's condition and deficits have worsened, Rebecca must now step down from her full-time role leading the charity foundation. Her relationship with her partner is also changing. It is not uncommon for her to have to hide her emotions, taking care not to trigger any stress that could worsen Matt's condition.

"Seeing your spouse decline is extremely painful. The doctors have warned me several times that he could lose his ability to speak", she says emotionally.

Her advice? Accept help.

"It's difficult, but essential. It's impossible to measure the cognitive, emotional, and psychological burden of caring for a brain cancer patient, with the personality changes that are involved."

She concludes:

"There needs to be full awareness, as well as clear information, provided directly by healthcare professionals to the patient and their loved ones."

"We guide new patients and help them get information. It’s a huge commitment"

Dirk, patient

Dirk lives with his wife and two daughters in a small village near Düsseldorf, Germany. Six years ago, his life was turned upside down when he was diagnosed with glioma.

Everything happened very quickly after that - CT scan, MRI, and surgery exactly one week later. The local hospital, where the tests were carried out, referred him to a larger medical center for surgery. However, when Dirk was discharged, he wasn’t given any information. The only instructions were to see an oncologist, who would monitor his progress.

"The results were shared with us three weeks later by a doctor who had to get the details over the phone from his colleague. We were completely shocked", he recalls.

Dirk then underwent six weeks of radiotherapy and twelve months of oral chemotherapy, which he tolerated well. Since then, he has regular monitoring with an MRI every three months at the University Hospital in Düsseldorf. This schedule is expected to continue for the rest of his life.

> **I didn't really have any symptoms, just a few headaches from time to time. But in 2019, I had an epileptic seizure and that's when it all started.**

For his loved ones, it is a relief. Although Dirk is not yet in complete remission, the progress is positive.

"I lost my sister to non-Hodgkin's lymphoma, which spread to all her organs, so my parents were afraid of losing their last child. But in December, it will be five years for me since it all began", he says.

Finding a new balance

On the professional side, Dirk returned to work six months after his operation, working remotely with the support of his employer and occupational physician. His only regret is having to give up high-intensity sports, such as volleyball and soccer, to avoid the risk of seizure. Isolated in a remote village with no public transportation, he also depends on treatment that is not always easy to get. Nevertheless, life has returned to normal, albeit a different normal.

He confides: ***"I don't show my emotions like I used to. I have trouble crying. Maybe it's a side effect of the radiotherapy."***

The couple's daughters, who were 7 and 10 years old at the time of diagnosis, have also been affected by the illness, naturally. To help them cope with the situation and give them a space to talk and share, the couple called on a local support team who has been a tremendous help.

Turning adversity into commitment

These days, Dirk has also joined a support group, which he co-facilitates as a volunteer.

"We guide new patients and help them get information. It's a huge commitment, but there aren't enough of us", he explains.

Looking back, Dirk knows what he needed most:

> **Real administrative support. Help is available, but you have to find it for yourself. No one really guides you. That's why I'm involved now—to inform patients about their rights. In Germany, a disability card gives you access to certain benefits, but you have to know about it. What's really missing is information.**

"The woman I got back after the operation was not the same "

John, caregiver

In 2001, John became a caregiver for his wife, now deceased, after she was diagnosed with glioblastoma multiforme. Twenty years later, he is involved in a patient association in the Netherlands, to help other families. His commitment stems from an experience marked by the severity of the shock, the lack of information, and the loneliness of dealing with the transformation of a loved one.

The diagnosis: It was like a jigsaw puzzle

It all began on a Friday evening in January 2001. John's wife had an epileptic seizure. The local hospital kept her in for observation. The next day, a neurologist broke the news of a brain tumor. It was a huge shock.

"It's a devastating thing to hear. Even if all the symptoms make sense", says John.

A neurosurgeon friend helped the couple get an appointment at a university hospital. The operation was scheduled for two weeks later. It was a period of limbo, in which they talked about the essentials: the future, their children, the funeral.

After the operation: A different person

Diagnosis confirmed. Surgery removed 75% of the tumor, but the rest was inoperable. No other treatment would be attempted, except for medication to combat possible epileptic seizures. But it was the aftermath of the operation that turned everything upside down. His wife was no longer the same person.

"We hadn't been warned that such personality changes could occur", John recalls.

He lost the person with whom, just a few days earlier, he had been having deep conversations. This mourning became a major source of suffering, one that he shares in the support groups he has been attending ever since.

> **How can you live with someone who is no longer quite herself?**

The fallout was huge. John stopped working to take care of his wife and their three daughters. His employer was understanding, but only for a while. John must insist that his family comes before work .

The children had to resume their daily lives pretty quickly. Then came the anxiety. Every headache became a source of panic. Each of them had to undergo an MRI, for fear of possible heredity.

Medical and social isolation

John describes a serious lack of information about the human and emotional consequences of the disease.

"They told us about the medical aspects, but never about what would happen afterwards", he remarked with surprise.

He also describes how difficult it was for those around him to believe him. His wife seemed “normal” to their friends. He felt that people dismissed his impressions or minimized the impact of the disease.

Twenty years on, John notes some positive developments, particularly in terms of access to information on the Internet. But families are often left to fend for themselves, especially when they're not in major hospital centers. And the harsh reality of having no medical choice remains.

> **If we hadn't done anything, she would have died in two to four weeks. That's not a real choice.**

"We were very lucky!"

Nick & Ashley, patient and caregiver couple

An epileptic seizure in the middle of the night abruptly turned the lives of engaged couple Nick and Ashley upside down. In a matter of hours, Nick went from being a young man in perfect health to a patient with a brain tumor. The couple took it in stride, adapted as best they could, and got through the ordeal with disarming clarity. Today, Nick participates in support groups for patients, while Ashley, a nurse, has remained by his side, supporting him every step of the way. Together, they have come to terms with the unacceptable and are adjusting to their new normal.

One night, one fall, and one devastating diagnosis

It was April 2020 when Nick fell out of bed in the middle of the night due to an epileptic seizure. After Ashley confirmed he had no history of epilepsy, he was taken to the hospital, where a scan revealed a tumor the size of four golf balls. Nick, who had never been sick, found himself in the middle of a life-threatening medical emergency.

> **At first, I thought he was joking, because he's always being funny. But then I realized it was very serious.**

In the days that followed, everything moved into overdrive. The operation was scheduled for Friday, just four days after the seizure. There was no time to hesitate or seek a second opinion. A decision had to be made quickly. Ashley took charge.

"She insisted that I return home before the operation. We drew up an advance care directive, so that we would be prepared for the worst while hoping for the best", Nick recalls.

Attentive healthcare staff

Thanks to her resourcefulness, Ashley was able to find an excellent neurosurgeon, check his references, and make sure every decision was the right one. At the same time, she took care of all the administrative issues.

The intense post-operative period included three months of speech therapy to regain Nick's ability to communicate. The treatment protocol worked well, and his neuro-oncologist made a rare decision to wait before starting intensive treatment, opting for a watch and wait approach rather than aggressive therapy. This strategy proved to be successful.

Life afterwards, from vigilance to gratitude

Currently, Nick has an MRI every three months, followed by a remote consultation.

He has returned to work and now lives a "normal" life, albeit a "different" one, as he has refocused on what is essential.

"This experience has made us more grateful every day", the couple acknowledges.

From private to public: Getting involved so you're not alone

Nick is involved in charity races, non-profit organizations and participates in patient support groups to share his experience.

As for Ashley, she has become an informed and active caregiver, without ever downplaying the difficulty.

The couple is once again looking forward to the future and is expecting a baby in January.

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