

## Epilepsy New Zealand

# Know Your Privacy Rights

### *Your Personal Information*

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## Epilepsy New Zealand – Privacy Statement

This privacy statement explains how Epilepsy New Zealand manages the personal information we collect about our clients, including what information we collect, why we need it, how we use it and who we might need to share it with. It also explains how we protect personal information and your rights to access or correct the information we hold about you.

### Who is Epilepsy New Zealand?

Epilepsy New Zealand is a registered Not-for-Profit, which exists to improve the social condition and quality of life for people with epilepsy, and those who care for them, along with increasing the knowledge of epilepsy in the wider community throughout NZ. A big part of our mission is to provide community-based epilepsy education and support through a network of educators. Our mandate requires us to collect personal information about our clients, both to deliver services and manage our wider outreach and engagement programmes. We know this information can be sensitive, and we value your trust in us as a custodian of your information.

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### What information do we collect about you?

The information we collect about you might include:

- Your name
- Contact information, including phone, email address and residential address
- Demographic information, including gender, ethnicity and occupation, if you choose to give it to us
- Date of birth
- NHI number
- Information about your GP
- Medical history information, including medications, when this is relevant to your epilepsy
- Information you choose to give us, including information about your epilepsy experience, your whānau, or other relevant lifestyle factors we need to know to support you
- Records of interactions we have with you, such as consultation notes or other file notes
- Relevant documents you provide to us, such as MRI scans
- Information that helps us ensure you and our educators are safe during in-person consultations, such as information about your property or information about Covid-19 vaccination status
- Information about your use of our website

## **What health information do we collect?**

We collect health information directly from our clients, and from third parties such as GPs, neurologists, or other healthcare providers. We make sure we only ask for information we really need to deliver our education and support services. Most of the health information we ask for is voluntary, but if you choose not to give us information, this may impact on our ability to deliver the support and services you really need.

Sometimes a family member, whānau, GP, or other health professional may give us information about you before we have spoken with you directly. When this happens, we will let you know, usually at or before our first contact with you, what was shared and why. You have the right to see and correct this information.

## **What information do we collect about website use?**

We use cookies (text files that are placed on your hard disk by our web server) to manage the way you can interact with our website, and better understand our web traffic. You have the ability to accept or decline cookies. Most browsers accept cookies automatically, but you can usually modify your browser settings to decline cookies if you prefer. If you choose to decline cookies, you may not be able to fully experience the interactive features of our website.

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## **How do we use your information?**

We only use personal information to deliver our mandate, including providing epilepsy education and support services to you and ensuring that we are effectively engaging with and supporting the wider NZ epilepsy community.

This includes using your information to:

- Understand your situation and needs, to provide you with the best possible information and support and facilitate your ongoing care
- Communicate with you about Epilepsy New Zealand, including keeping you informed with information relevant to your support and education
- Ensure your safety and the safety of our staff
- Meet the reporting requirements of our funding agencies, including the Ministry of Health and district health boards
- Contribute to ongoing health research, training, and quality improvement, including audit activities
- Support our outreach and community engagement activities
- Plan for ongoing provision of epilepsy services

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## **How do we protect your information?**

We are required by law to retain personal information about our clients for at least 7 years after the last contact we have had with you. Epilepsy can be a lifetime condition, and so clients may be registered with us and using our services for many decades. This means we may retain personal information for the lifetime of a client.

We use the Noted platform to process the personal information we collect. Noted is a trusted third-party cloud-based platform designed for health agencies, that assists us to securely store and use personal information to deliver services. Noted applies industry standard security measures to protect our information, and accesses and uses it only on our instructions.

We take all reasonable steps to protect the personal information we hold from loss, misuse or unauthorised access, modification or disclosure. Only Epilepsy New Zealand staff who need to see your personal information to deliver services can access it. This includes educators, contact centre staff and some senior managers. We also ensure that staff who need to deliver services offsite access the information they need via secure remote access to our systems, rather than carrying paper records.

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## **When do we share your information?**

Sometimes, to meet our purposes, we need to share personal information about you with third parties. We think it's important that you have no surprises about the way your information may be shared.

We may disclose personal information about you to:

- Other healthcare providers with a role in your care, such as your GP or neurologist
- Government agencies, such as the Ministry of Health, ACC, the Police, DHBs or the Ministry of Social Development, where required for reporting, administrative, legal, or research purposes
- Your whānau, where we believe this is necessary to ensure your safety and well-being, and where we have sought your consent or it is not practicable to do so

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## **Accessing or correcting your information**

You have the right to ask us for a copy of the personal information we hold about you, or to correct your information if you think it is wrong. You can also contact us if you have any concerns about the way we have managed your information, or if you just want to know more about our privacy practices.

Contact your educator or email us at [national@epilepsy.org.nz](mailto:national@epilepsy.org.nz) in the first instance.

If they cannot assist you, or are not available, call us on 0800 37 45 37, and we will get things sorted for you.

If we can't resolve your concerns, or you are not happy with our response to your access or correction request, you can also make a complaint to the Office of the Privacy Commissioner:

- Online complaint form: [www.privacy.org.nz](http://www.privacy.org.nz)
- Phone: 0800 803 909
- Writing to: Office of the Privacy Commissioner, PO Box 10-094, The Terrace, Wellington 6143

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0800 37 45 37

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