

Cystic Fibrosis WA Privacy Policy

Your privacy is of the utmost importance to us here at Cystic Fibrosis WA. This policy outlines our ongoing obligations to you in respect of how we manage your Personal Information.

CFWA collects information from people who are connected to our operations and activities including recipients of our services, donors, fundraisers, volunteers, and community members, amongst others. This privacy statement discloses what types of information we gather, how we securely store it, and how we use it.

1. Overview

1.1 CFWA is strongly committed to protecting the privacy of all our stakeholders.

1.2 CFWA is covered by the Federal Privacy Act 1988. As a Health Service Provider we align our Privacy Policy with the 13 National Privacy Principles (NPP's) as prescribed by the Privacy Amendment (Private Sector) Act 2000 (Act).

1.3 In short, personal information is information or an opinion that can identify an individual (including photographs). Personal information is defined in the Act to mean information or an opinion, whether forming part of a database or not, whether true or not and whether recorded in a material form or not, about an individual whose identity is apparent, or can be reasonably ascertained, from that information or opinion.

1.4 All personal information collected or held by CFWA will be treated in accordance with this policy.

2. Collection of information

2.1 The collection of personal information will be fair, lawful and executed in a reasonable, non-intrusive manner. CFWA collects personal information only if it is necessary for its functions and activities.

2.2 A person will be told at time of collection of their personal information:

- (a) CFWA's identity and contact details;
- (b) The purpose of the data collection;
- (c) How the person can access the information;
- (d) Any law that requires the personal information to be collected;
- (e) Consequences of not giving the information;

(f) The names of any individuals or organisations, if any, who will receive the information.

If CFWA obtains information about the individual from someone else, it will take reasonable steps to ensure that the individual is informed.

3. Use and disclosure of information

3.1 CFWA may only use or disclose personal information for the primary purpose for which it was collected, unless one or more of the following conditions is met:

- (a) The individual consents to the use or disclosure of the information.
- (b) The secondary purpose is directly related to the primary purpose of collection and the person would reasonably expect the organisation to use or disclose it in that manner.
- (c) The information is not of a sensitive nature and then may be used for direct marketing under specific circumstances specified in section 2.
- (d) The information is necessary for law enforcement, public or individual health and safety purposes.

3.2 CFWA may disclose health information about the individual to a person responsible for the individual if it is necessary to provide appropriate care or for compassionate reasons, the individual is physically or legally unable to communicate direct consent, and the disclosure is not contrary to the known wishes expressed by the individual.

3.3 A person is responsible for an individual if the person is:

- (a) A parent of the individual; or
- (b) A child or sibling of the individual and at least 18 years old; or
- (c) A spouse or de facto spouse of the individual; or
- (d) A relative of the individual, at least 18 years old and a member of the individual's household; or
- (e) A guardian of the individual; or
- (f) Exercising an enduring power of attorney granted by the individual that is exercisable in relation to decisions about the individual's health; or
- (g) A person who has an intimate personal relationship with the individual; or
- (h) A person nominated by the individual to be contacted in case of an emergency.

4. Quality of information

CFWA will take reasonable steps to ensure the personal information it collects, uses, and discloses is accurate and up to date. Should you wish to update your personal

details or obtain a copy of the information we hold on your record, see section 6 below.

5. Security of information

5.1 CFWA will take reasonable steps to protect the personal information it holds from misuse and loss, and from unauthorised access, modification or disclosure. Personal information that is no longer needed will be destroyed or permanently de-identified.

5.2 Personal information is de-identified before sharing with any third parties, except in cases where it is necessary to provide appropriate care or for compassionate reasons as outlined in section 3.

6. Accessing and updating of information

6.1 On request, a person or organisation may obtain the information we hold, for what purposes and how CFWA collects, stores, uses and discloses that information.

6.2 Accessing your information.

- a) CFWA will, upon request, provide access to an individual's own personal information in accordance with the requirements of the NPPs.
- b) Upon request, CFWA will let an individual see the personal information it holds about them and correct it if it is inaccurate.
- c) In some cases, such as when legally enforced, CFWA may deny a request to access or update your information. CFWA will provide reasons for denial of access or correction in accordance with the NPPs.

6.3 Updating your information.

- (a) CFWA will provide you with access to information we hold about you where this is possible and where it is necessary and lawful for us to do so. We will also take reasonable steps to update the information so that it is accurate, complete and current.
- (b) If you want to change any information that you have previously given to us, please contact our office using the contact information provided in section 15.
- (c) When you contact us, please include your email address, name, address, and telephone number and clearly describe your request. We will respond to within a reasonable period.
- (d) We reserve the right to charge you a reasonable fee for access to your information. These charges will be limited to the cost of recouping our expenses for providing you with your information, such as document retrieval,

photocopying, labour and delivery.

(e) If we decline your request to access your personal information or to correct it we will provide you with written notice setting out why your request has been refused and the mechanisms available to complain about the refusal. If you are not satisfied with our response, you may, at any time, refer your complaint to the Office of the Australian Information Commissioner at www.oaic.gov.au

7. Identifiers and Anonymity

7.1 CFWA will ensure that no Commonwealth Government identifiers (e.g. Tax File Numbers or Medicare numbers) are used as identifiers of individuals or their information, unless lawfully required.

7.2 When lawful and practicable, individuals will have the option of not identifying themselves when dealing with CFWA.

8. Sharing Data with Third Parties

8.1 CFWA will de-identify personal details when sharing your information with third parties, unless prior consent is given, or it is lawfully required. (E.g., in the course of providing health services, your information is de-identified when reporting to the Department of Health.)

8.2 CFWA will only permit cross-border data flows (information sent to an individual or organisation in another country) in accordance with the regulations of the Privacy Amendment (Private Sector) Act 2000.

9. Sensitive information

9.1 CFWA will not collect sensitive information* unless it:

- (a) Has the individual's consent; or
- (b) Is required by law; or
- (c) Is required to provide health services; or
- (d) Is necessary to prevent or lessen serious and imminent threat to the life or health of any individual, and consent cannot be obtained; or
- (e) Is necessary for research and statistics collection relevant to public health and safety, or management, funding and monitoring of CFWA

9.2 Sensitive information includes but is not limited to:

- (a) Racial or ethnic origin.
- (b) Political opinions.
- (c) Membership of a political association.

- (d) Religious beliefs or affiliations.
- (e) Philosophical beliefs.
- (f) Membership of a professional or trade association.
- (g) Membership of a trade union.
- (h) Criminal record.
- (i) Sexual preference or practice.
- (j) Health information. **

9.3 Health information is:

Information or an opinion about:

- (a) The health or a disability (at any time) of an individual; or
- (b) An individual's expressed wishes about the future provision of health services to him or her; or
- (c) A health service provided, or to be provided, to an individual; that is also personal information; or
- (d) Other personal information collected to provide, or in providing, a health service; or
- (e) Other personal information about an individual collected in connection to the donation, or intended donation, by the individual of his or her body parts, organs or body substances.

10. Information Obtained from CFWA Websites and Social Media

10.1 Visiting our websites:

We do not collect personal information from our visitors other than what is supplied to us on a voluntary basis. CFWA analyses our website logs to constantly improve the value of the content available on our website. Information in our website logs is not personally identifiable and we make no attempt to link that information with the individuals that browse our site.

10.2 Cookies

- (a) When you visit our websites, we may collect and store your computer's assigned IP address, the date and time of your visit, the information accessed and the referring page. We will also collect other non-identifying data for statistical purposes. This information is not linked to your personal information unless required by law.
- (b) Our website may use 'cookies' from time to time. Cookies are small text files that the website transfers to your computer through your web browser to enable the website's systems to recognise your computer. Cookies may also

be used to record non-personal information such as the date, time or duration of your visit, or the pages accessed, for website administration, statistical and maintenance purposes. Any such information will be aggregated and not linked to particular individuals unless required by law. You have the ability to accept or decline cookies by modifying the settings in your browser. Please note that some parts of the website may not function fully for users that disallow cookies.

10.3 Accessing our social media:

- a) Our social media accounts include, but are not limited to, Facebook, Instagram, LinkedIn and Twitter.
- b) By accessing our social media accounts, CFWA may collect person information associated with your accounts, such as your name, email address and location.

11. Regulation

11.1 CFWA has in place:

- (a) A privacy complaint handling system.
- (b) A freely available Privacy Policy on request.
- (c) A procedure to analyse data flow.
- (d) Staff privacy training.
- (e) Data security and a Data Breach Policy.

12. For CFWA the following applies:

12.1 Each individual's right to their privacy and confidentiality are respected. They also have a right to access their personal information held in accordance with the NPPs and the attached Procedure.

12.2 Each individual or the legal guardian is informed of the Privacy Procedures and effort is made to ensure that they understand their rights in relation to these Procedures.

12.3 Each individual or a person authorised by such, or the legal guardian has access to personal information held by the relevant organisation within the constraints of the NPPs.

12.4 All CFWA staff and volunteers sign a Confidentiality Agreement.

12.5 Third party providers who may gain access to personal information through our contracted services with them are required to sign a third-party confidentiality agreement, or provide alternative acknowledgement of these obligations. (E.g. personal trainers, cleaning services)

12.6 Individuals can request access to their personal information held by CFWA.
12.6 Any complaints regarding privacy, confidentiality and access to information breaches are reviewed and documented. Please refer to section 14.

13. Code of Conduct for Staff

13.1 All staff members will respect the privacy of users and hold personal information obtained in the course of their duties in confidence except where the law demands otherwise, or there are ethical or moral reasons not to do so and disclosure is permitted under NPP 2, or where the individual specifically consents to the disclosure.

14. Making a Complaint

14.1 If you wish to make a complaint, or you have any question regarding this policy, please contact our CEO. We will respond to your complaint or enquiry as soon as reasonably possible. Our aim is to resolve your complaint or enquiry quickly and to your satisfaction. However, if you are not satisfied with our response, you can contact the office of the Privacy Commissioner who may investigate your complaint or enquiry further.

14.2 Our CEO can be contacted via these channels.

- a) Email at ceo@cfwa.org.au
- b) Online at www.cfw.org.au/about-us/contact
- c) Phone **08 6224 4100**
- d) Mail at **PO Box 959, Nedlands 6909**

15. Contacting us

15.1 To contact us regarding updating your personal information or to obtain a copy of your personal information we have collected, please contact admin@cfwa.org.au or **08 6224 410**.

15.2 For more information about privacy in general, you can visit the federal privacy commissioner's website at www.oaic.gov.au