



Red Magazine

Quarterly magazine with personal member stories, research and information. To join our mailing list please contact digitalmarketing@cfwa.org.au



Red E-News

Fortnightly e-news about current CF issues and events. To join our mailing list please contact digitalmarketing@cfwa.org.au



Community Fundraising Events

CFWA supports community initiatives to raise funds for services and research. To become a fundraiser or volunteer contact events@cfwa.org.au



Contact

▶ events@cfwa.org.au for information on holding a fundraiser.

We also run a number of our own annual fundraising events:

- Cystic Fibrosis Golf Classic
- 65 Roses Day

A Guide to Services for:

Families & Children



For more information about services and programs contact servicesmanager@cfwa.org.au or phone 6457 7333

Contact us

- ▶ cysticfibrosis.org.au/wa
- ▶ facebook.com/CysticFibrosisWA
- ▶ twitter.com/CysticFibrosis1
- ▶ youtube.com/cysticfibrosiswa
- ▶ 08 6457 7333
- ▶ info@cfwa.org.au
- ▶ Look for "Cystic Fibrosis WA" under Hospital and Health Care
- ▶ The Niche Building, Suite C, 11 Aberdare Road, cnr Hospital Ave Nedlands, WA 6009

Cystic Fibrosis WA

Cystic Fibrosis WA (CFWA) is a not-for-profit organisation with a mission to contribute to the social, physical and emotional wellbeing of those affected by cystic fibrosis (CF) in WA and to assist in the advancement of research.

We deliver regular and essential services to many families living with CF in WA. Our team includes: Services Manager, Social Worker, Physiotherapist, Community Nurse, Nurse Educator, Education Officer, Health Promotions Officer and Recreation Officer.

Membership of CFWA is free and you can sign up here: www.cysticfibrosis.org.au/wa

This brochure specifically addresses how CFWA can support children and young people with CF and their families.

Home Care Worker (HCW) Program: Metro and Bunbury

HCWs provide flexible and supportive in-home care, in line with hospital best practice. These services include:

- Airway clearance support
- Assistance with exercise programs
- Nebuliser support
- Occasional respite for parents

Personal Trainer (PT) Program

Our PT provides a specific and targeted, in-home exercise program. This program is run in collaboration with the hospital physiotherapist. It is available to individuals aged 16 and over only.

Nurses and Physiotherapist

Available for assistance with:

- General advice
- Treatment routines
- Nebuliser assistance
- Motivation
- Pill swallowing
- Health coaching

Social Worker

Available for assistance with general support.

E-Mentoring Program

This program links up young adults with CF to an older, more experienced person with CF who can provide structured guidance and support. It is available to individuals aged 16 and over only.

Subsidies

- Country Patient Travel Subsidy – \$50-100 per clinic or hospital visit to assist with fuel, parking and food.
- Patient Support Subsidy – \$200 annual subsidy to assist with the purchase of items such as medical/exercise equipment or gym/sports memberships.

All subsidies are subject to availability.
www.cysticfibrosis.org.au/wa/subsidies

Hospital Support

- Hospital in the Home (HiTH)- Assistance with HiTH following referral from Perth Children's Hospital (PCH).
- Inpatient visits to offer support and deliver a Hospital Support Bag.

Regional Support

Trips to regional areas to provide:

- Education – Families, day cares, schools and health professionals
- Social events – Dinners and coffee catch ups with members
- General support to families and individuals

Equipment Loans

Fast acting nebulisers are available for short term loan from CFWA, in consultation with PCH.

Recreation Events

CFWA run a range of annual events for carers:

- Ladies High Tea – A support event for female carers
- Sibling and Offspring Camp – A camp for siblings and children of people with CF, aged 8-16
- Parents' Retreat – Weekend getaway for parents
- Parents' Dinner – Support dinner for parents

www.cysticfibrosis.org.au/wa/support-events

Education

We can provide education to:

- Extended family
- Day cares
- Schools
- Workplaces and other community groups
- Health professionals

Newly Diagnosed Program

Our Newly Diagnosed Program offers support to families following the initial diagnosis of CF. This may include;

- Newly Diagnosed Support Pack – Includes information resources and baby items (delivered by PCH)
- Home visits from our community nurse, physiotherapist and/or social worker
- HCW support
- Information – Cystic Fibrosis: New Diagnosis Information for Parents booklet

Transition Program

Our Transition Program provides assistance for young adults transitioning from PCH to Sir Charles Gairdner Hospital (SCGH). The program includes:

- Tour of SCGH respiratory ward and clinic
- Introduction to new CF care team
- Information and resources

Information and Resources

CFWA have developed a range of educational resources including:

Education:

CFSmart

A series of resources for teachers, parents, students and allied health professionals.

www.cfsmart.org

CFFact

A range of factsheets on various CF related topics.

www.cysticfibrosis.org.au/wa/fact_sheets

Exercise:

CFFit

A set of exercise resources to assist with exercising at home or in the gym.

www.cysticfibrosis.org.au/wa/cffit

Nutrition:

CFFood

A set of nutrition resources to assist with age appropriate dietary information and planning.

www.cysticfibrosis.org.au/wa/cffood

CFCooking

Short films featuring people with CF and dietitian cooking healthy CF food.

www.cfcooking.org

Seminars and Expos:

CFWA host various education events each year. Seminars are filmed and available on our YouTube page.

www.youtube.com/cysticfibrosiswa