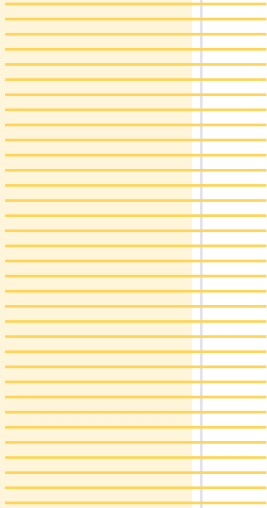




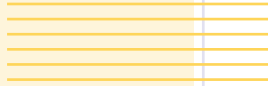
Angelman Syndrome Association

Incorporated Australia



Angelman Syndrome

Information Package for
Families, Carers, and Professionals



1st World Conference

The 1st World Conference of the IASO was held in Tampere, Finland from Tuesday July 4 2000, through to Saturday July 8 2000.

(Reprinted from the International Angelman Syndrome Organisation Website - Webmaster Heikki Taimio on the server space provided by Harold Anderson)

2nd World Conference

The 2nd World Conference was held in Washington, U.S.A. from July 1-5, 2003. 360 people attended including 52 from 19 countries outside the U.S.A. Dr Ellie Smith attended as the Australian Angelman Syndrome Association representative. She reported on significant research being undertaken in the U.S. including The Angelman Project. This research project involves collection of data from all the Angelman clinics.



Overseas Angelman Syndrome Associations

International Angelman Syndrome Organisation <http://www.international.angelmansyndrome.org>

Angelman Syndrome Foundation (ASF) - USA <http://www.angelman.org/>

Angelman Syndrome Support Education And Research Trust (ASSERT) - UK
<http://www.angelmanuk.org/>

Canadian Angelman Syndrome Society (CASS) <http://www.angelmancanada.org/>

Overseas Personal Websites - this list is not exhaustive go to the links page on the IASO website for a complete, up to date list –
<http://www.international.angelmansyndrome.org/aslinks.html>

Amburgy's Angels on Earth <http://members.tripod.com/mariahndarci/index.htm>

Harold Anderson's Asclepius site (USA) <http://asclepius.com/angel/>

Marc Bissonette (Canada) <http://www.armyofangels.org/>

Cheryl Briggs Angeland site for siblings (USA) http://www.angeland.org/Angeland_Home.html

Heather's Angel Land Page <http://www.angelfire.com/ok/HeathersAngelLand/>

Julie Hyman's Angels Among Us (USA) <http://www.home.earthlink.net/~julhyman/angel.htm>

Michel and Lori Marcotte (Canada) <http://www.multimania.com/angelman/index-2.htm>

Juan & Maria Palomares (Spain) <http://www.angel-man.com/>

Beth Sturr <http://www.bethsturr.com/>

Frank van Hof - Heaven must be missing an angel... ((Netherlands)
<http://people.zeelandnet.nl/fhof/angelman.htm>

Further information about Angelman Syndrome on the Internet

Advocacy and Education: How AS Families Can Help Establish School Programs Best Suited to Their Children's Needs - Hal Lippman (USA)
<http://www.international.angelmansyndrome.org/hallippman.html>

An Evaluation of Play Development in Children and Adolescents with Angelman Syndrome - Angela Reason (UK)
<http://www.international.angelmansyndrome.org/angelareason.html>

Angelman Syndrome: Family and Social Issues -Elfinn Faerevag (Norway)
<http://www.international.angelmansyndrome.org/elfinn.html>

Angelman Syndrome Foundation: Facts about Angelman Syndrome: Information for Families: (ASF - USA)
<http://www.asclepius.com/angel/asfinfo.html>

Andrew - a Gift of Love, Laughter and Hard Work - Simone Kennedy (Australia)
<http://www.international.angelmansyndrome.org/simonekennedy.html>



Further information about Angelman Syndrome on the Internet (continued)

Augmentative Communication -(USA)
http://www.augcominc.com/articles/8_3_angelmans.html

Bibliographies on Angelman Syndrome - Michel Marcotte (Canada):
<http://www.multimania.com/angelman/2bibliog.htm>

Jill Clayton-Smith: Angelman Syndrome in Adulthood: (UK)
<http://www.angelman.dk/page16.html>

Designing and Creating an Environment for Angelman Children -Juan J. Palomares (Spain)
<http://www.international.angelmansyndrome.org/juanpalomares.html>

Diagnostic criteria for Angelman Syndrome (ASF - USA)
http://www.angelman.org/diagnostic_criteria.htm

Epilepsy in Angelman Syndrome - Terry Hutchison (USA)
http://www.angelman.org/seizures_in_children_with_as.htm

Expressive Communication - Robyn Alvares (USA)
<http://www.international.angelmansyndrome.org/assurvey.html>

Genetics 101 of Angelman Syndrome: Charles A. Williams (USA)
<http://www.asclepius.com/angel/genetics101.html>

Julie Hyman - Angelman Syndrome A to Z (USA)
http://www.home.earthlink.net/~julhyman/atoz/atoz_home.htm

John Miles: Angelman syndrome information:
<http://people.zeelandnet.nl/fhof/angelman/asi.htm>

Michel Marcotte "What is Angelman Syndrome?": (Canada)
<http://www.multimania.com/angelman/index-2.htm>

Siblings of Individuals with Angelman Syndrome - Understanding, Supporting & Empowering
- Julie Hyman (USA)
<http://www.international.angelmansyndrome.org/juliehyman.html>

Sleep Problems in Individuals with Angelman Syndrome - Wagstaff et al (USA)
<http://www.international.angelmansyndrome.org/wagstaffsleep.html>

Martha Spowles: Angelman Syndrome, a Parent's Brochure for Parents: (USA)
<http://www.asclepius.com/iaso/angelmanessay.html>

Beth Sturr - Hints and Ideas for Everyday Living for Parents of Angelman Children (USA)
<http://home.att.net/~tomsturr/wsb/main.htm>

The UBE3A Gene and its Role in Angelman Syndrome: Celle et al (USA)
<http://www.asclepius.com/angel/ube3a.htm>

Advocacy <http://www.geocities.com/Heartland/Garden/1583/>

Carers Australia - Resources and support for carers
<http://www.carers.asn.au/index.html>

Challenging Behaviour Gentle Teaching - Behaviours
<http://www.users.bigpond.com/websterpaul/cb.htm>
<http://www.inala.org.au/behaviour/index.htm>

Communication Aids - PECS, AAC devices, Sign Language, Makaton
<http://www.users.bigpond.com/websterpaul/comms.htm>

Epilepsy - Australian State Associations & resources
<http://www.users.bigpond.com/websterpaul/Epilepsy.htm>

G-Tube (Feeding) <http://www.challengenet.com/~g-tube/>

Kidsafe - safety around the home <http://www.greenweb.com.au/kidsafe/>

Kyphosis <http://www.spinaldoctor.com/scoli.htm>

Melatonin for Sleep Disorders <http://www.melatonin.com/home.html>

Mobility Aids <http://www.users.bigpond.com/websterpaul/mobility.htm>

Scoliosis <http://www.spinaldoctor.com/scoli.htm>

Sleep Disorders - Melatonin <http://www.melatonin.com/home.html>

Sterilisation and your child's rights www.hreoc.gov.au/disability_rights/sterilisation/index.html

Wills http://lawsocnsw.asn.au/resources/lcj/archive/feb1996/63_1.html

Toilet Training <http://www.unc.edu/depts/teacch/toilet.htm>

Federal and State Government Departments - Disability related

Federal

Centrelink <http://www.centrelink.gov.au>

Family and Community Services (funds federal programs such as supported employment, CSTDA (Commonwealth State & Territories Disability Agreement) funded services)
<http://www.facs.gov.au/>

Human Rights and Equal Opportunities Commission
<http://www.hreoc.gov.au/>

Office of Disability
http://www.facs.gov.au/internet/facsinternet.nsf/who/branches-office_of_disability.htm

State Government Disability Departments

ACT - ACT Community Care	http://health.act.gov.au/c/health?a=sp&did=10037235
NSW - Ageing, Disability and Home Care	http://www.dadhc.nsw.gov.au/DADHC
NT - Aged & Disability Services	http://www.nt.gov.au/health/comm_svs/aged_dis_ccs/aged_dis_ccs.shtml
QLD - Disability Services Queensland	http://www.disability.qld.gov.au/
SA - Human Services	http://www.dhs.sa.gov.au/
TAS - Health & Human Services	http://www.dhhs.tas.gov.au/index.php3
VIC - Human Service	http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/
WA - Disability Services Commission	http://www.dsc.wa.gov.au/



Managing Money

Carers are usually family members who provide support to children or adults who have a disability, mental illness, chronic condition or who are frail aged. Carers can be parents, partners, brothers, sisters, friends or children of any age. Carers may care for a few hours a week, or all day every day. Some carers are eligible for government benefits, while others are employed or have a private income. Caring has many direct and hidden financial costs, which stretch the budget. Financial assistance is available to offset or directly subsidise some of the costs, even if only to a small extent. However, with or without financial assistance, managing money is an important part of the role of most carers.

How do I get financial assistance?

Many carers do not apply for financial assistance because they are unsure who to contact or are put off by the procedures. Don't feel ashamed or embarrassed about asking for assistance. If you do not, you and the person you are caring for could lose out on money specifically allocated by government for helping people who are ill, have a disability or who are frail aged.

A good starting point for help and information about financial assistance is your local Carer Resource Centre which can be contacted on the free call number 1800 242 636.

You can also call Centrelink on 13 27 17 or their Financial Information Service on 13 23 00. The Centrelink Multi-lingual Service can be contacted on 13 12 02.

What sort of financial assistance is available?

You, or the person you are caring for, may be eligible for some of these payments and concessions.

Centrelink

- Carer Payment:

For carers who are caring on a long-term basis for an adult or child who has a disability, is chronically ill, or is frail aged and needs full-time care and attention. This payment is income and assets tested, and eligibility is dependent on an assessment of care needs.

- Carer Allowance:

For carers who are caring on a long-term basis for a child or an adult who has a disability, is frail aged, or is chronically ill and lives with them. There is no income or asset test for this payment and it is tax-free. It can be paid in addition to other Centrelink payments such as Carer Payment or Age Pension.

- Disability Support Pension:

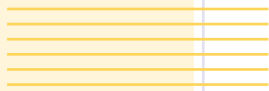
For people who are unable to work full time for at least two years because of a disability and who are 16 years of age and over.

- Concession Cards – Pensioner Concession Card (PCC) & Health Care Card (HCC):

You, or the person you care for, may be entitled to one of these cards if a payment is granted. PCC and HCC cards entitle the holder to many concessions including prescription medicines, transport fares, rates, power bills and car registration.

- Rent Assistance:

For people who get a payment such as the Carer Payment and pay rent for private accommodation.



- Pensioner Education Supplement (PES):
For people who receive the disability support pension attending school, TAFE or a university for at least eight hours per week. This applies from the age of 16 years into adulthood.
- Mobility Allowance:
For people who travel to and from their home in connection with work, training or job search activities. The person would be working (including voluntary work) or undergoing vocational training for at least eight hours a week.
- Pharmaceutical Allowance:
For people who receive the Disability Support Pension or a Parenting Payment.
- Remote Area Allowance:
For people who live in the remote areas of Australia that makes them eligible for this allowance.

NOTE: If your child is not living with your family (e.g: in supported accommodation) then they will be eligible for some of the above payments that you as a parent would not normally be entitled to.