

DISABILITY NEWS

Vol. 3 Issue 1 June 2007

 **UnitingCare**
South Australia

email: trevor@sa.uca.org.au

from the Editor....

Greetings!

On the back page of this issue Tony Wong, a person who has lived with paraplegia for over 30 years, is cited as saying: *If you fail to see the person, but only see the disability, who is blind?*

To put it another way, if you only see the wheelchair, the struggle to walk or talk, or the seeing eye dog, and if you only see someone with Down syndrome as "a Downs" (see "Living with Eddie" p.4) you are failing to see all that that person has to offer, including their loves, values and talents, and everything else that comprises their humanity.

Yes, it is very important to see the struggles that accompany life in a wheelchair. Without seeing this we cannot appreciate nor respond effectively to that person, at their point of need, if required.

But it is also important to see the whole person if we seek to move from pity or indifference to the potential for a mutually embracing relationship

Feel free to share this newsletter with your friends., or contact me for extra copies.

If you haven't already indicated, let me know if you would prefer to receive this electronically.

Email me (address above) with the names of anyone who would like to be added to the mailing list.

Your feedback is always welcome.

Enjoy the read.

Rev Trevor Whitney

Disabilities Ministry Chaplain
UCA, Presbytery & Synod of SA
UnitingCare Commission

Who is this person I see? Sophie's story

Who is this person I see sitting next to me, soaking up the afternoon light as it pours in through the windows of this institution?

... an aging woman by name of Sophie—frail, far away expression
... thinning grey hair, loose, weather-beaten skin, slightly hunched
... a sufferer of strokes some years ago
... a struggler for words and thoughts—frustrated, so frustrated
... so dependent—for feeding, washing, toileting, so much
... so dependent—on doctors, nurses, speech pathologists, dieticians,
and all the rest of the health care artillery
... and a loner—a weary loner.

I find myself in her bedroom, 5 metres by 3—Sophie's world.

She points to a book of clippings, pictures, and type-written notes — I see a career that's taken her to North America and Fiji—fine achievements, many colleagues and companions from across the oceans.

I turn to the opposite wall to observe a framed education degree, a large certificate of appreciation from North America hanging above a large, and a beautifully hand-crafted fruit bowl, with a plaque denoting best wishes from Fijian friends.

Above her head I see a painting of Jesus washing his disciple's feet, signed by Sophie.

I see old photos. She nods—it's young Sophie with her parents.

I see craftwork, mementos, treasured books, and so much more.

This room is like the gallery of this woman's proud and rich life.

I no longer simply see a rather vacant, aging, weary woman, wholly dependent on others for the failures of her body and mind.

I see a dignified woman, a dignified woman who has lived, loved, taught, learnt, experienced joy and grief, success and failure.

I see a proud woman who has

gently shown me she is not to be contained by my limiting clichés and naïve first impressions.

Who is this person I see?

A giver of grace to me.

Trevor Whitney
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**Check out the new
Disability Resource Website, p.4 !!**

MOTOR NEURONE DISEASE

* **What is it?** MND is the name given to a group of closely related diseases affecting motor neurones, i.e. the nerves controlling muscles.

* **What are the symptoms?** They can vary but early symptoms may include twitching, cramps, general fatigue, muscle stiffness and jerking of arms and legs.

* **How does it progress?** Progress is steady. An average course is 3-4 years, but length can vary.

For any enquiries about Motor
Neurone Disease you can contact the
MNDA (SA)

23a King William Rd.,
UNLEY SA 5061

Phone: 08 8357 0245
Fax: 08 8357 0265
FREECALL: 1800 777 175

Email: admin@mndasa.com.au

Internet: www.mndasa.com.au



the logo of the
Motor Neurone Disease Association SA,
with their stylised national symbol,
the Blue Cornflower - a symbol of hope

logo used with permission

Motor Neurone Disease Association (SA) Annual Service of Thanksgiving & Remembrance

For many years now the Motor Neurone Disease Association (SA) has held a Service of Thanksgiving & Remembrance for those who have died in recent years from Motor Neurone Disease (MND). The service is held at the Julia Farr Services chapel, Highgate, and is attended by the loved ones of those who have died from this disease.

The service provides an opportunity for family members and others to come together over a service of worship, followed by informal fellowship, and to gratefully acknowledge and remember the life of their loved one.

In the service there is opportunity to light a candle of remembrance, and receive a packet of 'Blue Ball' cornflower seeds (the floral emblem of the MNDA), with the invitation to plant the seeds, and in watching them grow, to be nurtured in the memory of their loved one.

Also, on display at the service is a 'March of Faces' banner that includes the faces of those who have died from MND in recent years.

Over the years hundreds of people have attended this service in order to honour and keep alive the memory of loved ones who have died from MND.

Prayer of Thanksgiving & Remembrance

Leader: Creator God, we remember and give thanks for loved ones who have died, those whom you graced with many gifts. May we too share our gifts. Creator God, hear our prayer.

Response: **Creator God, hear our prayer.**

Leader: Patient God, we remember all those who bore their pain with dignity. Help us likewise bear our burdens in life's journey. Patient God, hear our prayer.

Response: **Patient God, hear our prayer.**

Leader: Caring God, we give thanks for all who have cared, and who have given of their compassion to make each day special. May all of these be blessed. Caring God, hear our prayer.

Response: **Caring God, hear our prayer.**

Leader: Comforting God, we pray for those who are on a new journey. Grant them your deep, abiding peace. Comforting God, hear our prayer.

Response: **Comforting God, hear our prayer.**

All: **Amen.**

Adapted from a prayer commonly used in the
MNDA (SA) Annual Service of Thanksgiving and Remembrance



Developing Programmes
that Include Children
with a Disability in the
Life of the Church

What is inclusion?

It's much more than just being 'present' in the activity or program.

It incorporates involvement, contribution, active participation, making choices, sharing skills, being recognised, valued, serving, relating and belonging.

Becoming more inclusive:

Key factors to consider:

- ◆ Consulting with parents – building positive relationships and encouraging open discussion
- ◆ Adapting the environment – check accessibility, space, height of tables, width of doorways, visibility etc.
- ◆ Resources – adaptive equipment may be needed, more appropriate materials, extra helpers, etc.
- ◆ Attitude/beliefs/values – creating positive and sensitive attitudes, beliefs and values
- ◆ Support/assistance – identifying needs and providing adequate support
- ◆ Adequate planning and flexibility – consider time available, adapting activities, suitable equipment, etc.
- ◆ Leadership team – consider numbers, abilities and confidence of team. Provide information and training.
- ◆ Eliminate barriers – physical, social and attitudinal.

Remember that at the heart of every child is the deepest desire to belong, to be accepted and to be approved of. With this in mind, your loving, positive, cheerful, natural, encouraging and honest manner are all qualities that will make a difference to every child regardless of ability or disability.

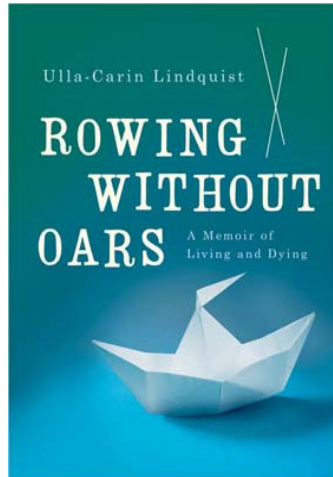
Edited version of article
by Daphne Quadrio
KUCA News, Autumn '05, p.19
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Reviews Reviews Reviews

ROWING WITHOUT OARS

Ulla-Carin Lindquist



John Murray (Publishers)
London, 2005
hardcover \$21.95

available through all good bookstores

Ulla-Carin Lindquist had so much to live for. She had a devoted husband, four adoring children, and a successful career as a newscaster. Yet, as she approached her fiftieth birthday she began to notice small muscular failures, including strange numbing sensations in her hands and arms. Soon she was diagnosed with Lou Gehrig's Disease, an aggressive form

of Motor Neurone Disease. Ulla-Carin begins to chronicle her failing health, her grief, her family relationships, and, ultimately, her acceptance of dying. In the face of this incurable, degenerative disease that leads to ever-increasing dependency upon the help of others, we become privy to personal phone calls between mother and daughter, afternoons with husband and sons, the valuing of loved smells, and, of course, the horror associated with every discovery of muscular deterioration. And amidst all of this we hear Ulla-Carin and other family members articulate the fragility and preciousness of life.

This book beautifully and very personally articulates the universal themes of love, life, death and those relationships we hold dearest, especially family. The chance to hear a first-hand account from someone who is living and dying with such an aggressive disease is a rare privilege.

*"Today I'm checking over my life insurance.
But, I can laugh.
Hug my four children, or at least lift my left
arm so that I can touch them.
Hug my husband, and kiss him with my semi-
paralysed mouth.
Read.
Listen to music.
Breathe fresh air.
Wander in the labyrinth of my memory.
Listen to friends.
Peace . . . ?
Feel peace within me!*

Ulla-Carin Lindquist, "Rowing Without Oars," pp.130-31

“Living with Eddie”

Simon Barnes

Weekend Australian - April 14/15, Magazine, pp.30-33

The author is the senior sports journalist for the *London Times* newspaper. However the article is not one of the author's incisive sports columns, but represents his reflections on living with a child born with Down syndrome.

He speaks honestly, describing how nothing could have stopped his wife caring for and loving Eddie, but that, to begin with, if he had been married to a wife who sought termination, he would have acquiesced, and become one of those who pitied parents who had a child with such an impairment. - And he states, “..... *But, thank God, I did not marry someone else.*”

Simon describes Eddie's first few months of illness, his slow but continuous education, his frustrated attempts at communication, and his gift of joyous laughter.

He affirms Eddie's worth not in terms of how he compares for genius alongside the modern day Mozart, van Gogh or Einstein, but that his function, along with that of the rest of the human race, is to both give and receive love, and for that we are all the better.

Along the way Simon dispels some of the misplaced attitudes that are projected onto people with impairments such as Down syndrome. Such as describing people like Eddie as “them”, or as “a Downs”, i.e. as a thing, rather than as the unique human being which he is.

This is a beautifully written article which adds much needed wisdom as to children born with Down syndrome, as well as the sensitive insights of loving parents.

This article is taken from “All about us!” - a book about learning disability, compiled by Brian Rix, and published by Mencap. Hardback . Hardback \$48.70, softback \$29.20. Order through www.mencap.org.uk/allaboutus

“I don't have a child with Down syndrome; I am Eddie's father. There is a huge amount of difference between the two things.”

**Simon Barnes
“Living with Eddie”**

PRIVATE AND CONFIDENTIAL

by **Marion Ripley**

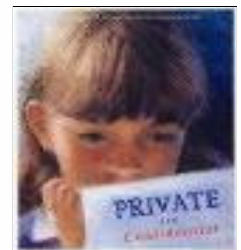
published by Francis Lincoln Publishers

2005

soft cover \$14.95

available all good bookstores

When Laura gets her first letter from her new Australian pen friend she's delighted. She writes to Malcolm but doesn't receive a reply.



Finally Malcolm's sister writes telling her that Malcolm has gone into hospital for an eye operation, as he's nearly completely blind. Laura decides to learn Braille so she can send him a get-well card. Soon they are corresponding in Braille, making their letters private and confidential. Including an information spread about Braille and a Braille sample, this book shows children that having a disability should not be a barrier to friendship, and that communicating in a different way can be fun.

WHO IS DISABLED?

If you fail to see the person, but only see the disability,
who is blind?

If your heart & mind do not reach out to your
neighbour, who is handicapped?

If you cannot hear your brother's cry for justice,
who is deaf?

Tony Wong, Jamaica
paraplegic since 1976
cited by Peter Millar, “The Iona Prayer Book”

New Disability Resource Website

www.sa.uca.org.au/goto/disability

Available on the Uniting Church SA website this site offers disability-related resources helpful for those engaged in worship, Christian Education, small groups, children's ministry, as well as personal reflection.

Areas listed include Book Reviews, Disability News newsletter (back copies), Kid's Books, Liturgy, Prayers, and Stories.

More content and pages will be added over time.

Your comments are welcome and can be addressed to trevor@sa.uca.org.au.

Add it to your “Favourites” !!