

DISABILITY NEWS

Vol. 4 Issue 1 July 2008

 **UnitingCare**
South Australia

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from the Editor....

Greetings!

When we buy a product at the supermarket the label on the packaging, along with all its consumer information, is meant to tell us exactly what we're buying. That kind of label can be helpful.

But sometimes labels can be applied to people, and it can be harmful, stereotyping people in hurtful ways.

This can certainly apply to people with a disability. Jenny points this out in her poem (p.2) concerning the negatively regarded labels of "other" or "disabled."

And what of the highly successful subject of our book review (p.3), Jean-Dominique Bauby, who, following a massive stroke, and acquiring almost total paralysis, could easily be labelled as "helpless", despite his active mind and very creative imagination.

Acquiring a major disability is tough. Acquiring labels as well is even tougher.

Let's leave the labels for the supermarkets, and allow those easily tagged as "different" to be free to live life well.

Feel free to share this newsletter with your friends.

If you don't already, 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 SA

A Sincere Welcome - Ted's Story

A man from our church recently came home from a tour of duty in Afghanistan. He had left optimistic and enthusiastic. He arrived home thin, crushed and numb. He asked that his return not be mentioned in the service because he couldn't cope with the attention from well meaning but insensitive people. He said hello to people but retreated from any conversation of significance. Then he escaped to the toilets, that haven we go to when it is hard to face people.

A week later he told me how hard it was to re-adjust to western culture and to deal with what he had seen abroad. Then his face softened as he told me about how my son Ted had greeted him that first week at church.

Ted has Down Syndrome, and is one of the chief welcomers at church. That is not because he is on the roster but because of who he is. He says hello to everyone. He has short conversations about the footy or the weather or asks people about their week. He remembers the names I forget. He speaks to important and unimportant people alike.

When our soldier friend returned, Ted sidled up to him and commented, "You've been away."

"Yes."

Ted simply said, "I missed you," and gave him a hug. They stood together quietly for a while.

As this broken man retold the story, his eyes filled with tears. He said, "Nothing made me feel so welcome. No-one was more sincere. I believed what he said and I didn't worry about what Ted thought about the troops or how I looked or how well I was coping. He just accepted me and didn't press me to talk about it. I loved that."

So often we see people with disabilities as people we have to help, especially those with intellectual or very severe disabilities. We can be blind to the gifts they have, and may miss the opportunity to be ministered to by them. What an extraordinary thing to belong to the body of Christ! Let's keep our eyes open and hearts humble to receive such ministry.

Suzanne Foley, Ted's Mum
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Disability Resource Website www.sa.uca.org.au/goto/disability

Available on the UCA SA site, it has been recently updated. Includes Prayers, Stories, and Reviews.
Contains a new page, Disability Ministry.
A resource for church & personal use.

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When we think of the place of people with disabilities in the local church we often think in terms of strategies.

- Do we have adequate disability car parking?
- Do we have appropriate access to and spacing within our church buildings?
- How can we most appropriately assist people with disabilities to feel included in our church programmes and ministries?

The successful answering of such questions is important if people with disabilities are going to feel included in the life of our congregations.

But if such people are to feel truly welcomed there is something crucial that needs to happen before any such strategising.

As John, a volunteer who assisted people in wheelchairs to get to church, said in a church meeting, "**we could remember to look them in the eye**".

What did he mean by this? - He was saying that in the church, as elsewhere, people with disabilities are often thought of as those, who because of their disabilities, need to be served. Whether its pushing a wheelchair, assisting with a meal, or some other daily task, people with disabilities are often thought of as needing assistance, there to be served.

But what is most important for all of us is developing personal, loving relationships with one another.

Some feel that forming personal relationships with people with disabilities is difficult because, "they're different," but is it really?

As with all of us building a personal relationship with a person with a disability can begin quite simply by stopping what we're doing and,

- Looking the person with the disability in the eye, and then, perhaps,
- Saying hello and offering a word of welcome, and then perhaps,
- Offering a smile ... and then, just perhaps, there is the seed of a genuine personal friendship.

This is not to say that there may be practical issues that need attention in forming such a relationship, including the pushing of a person in a wheelchair to church. Words of welcome without practical support may justly be regarded as hollow.

However, amidst such tasks, and amidst our plans to enable people with disabilities to feel included in our churches, **may we remember to look that person with the disability in the eye.**

Trevor Whitney

A New Path

The following poem was composed by Jenny Charlesworth upon being diagnosed with a physical disability in late 2007:

Lord, I am on a new path
 A path that is narrow & rough
 Where each step is slow and laboured.
 An unexpected path
 Breaking me out of my comfort zone
 Bringing new challenges & different priorities.
 The struggle as I journey brings discomfort & frustration.
 I've always been a part of the majority "we"
 I could go unnoticed, anonymous
 With the freedom to be selfishly independent.
 But now, Lord, I'm one of those "others"
 Labelled, stereotyped as "disabled"
 Standing out from the crowd.
 Needing to ask for help, having to rely on others all the time
 Getting tired quickly, not able to do what I once could
 I don't like it, Lord. I feel uncomfortable
 I'd much prefer to be "normal", just blending in,
 Moving easily with the crowd.
 But I'm here now on this different pathway
 I'm not sure where it is leading
 There are not many fellow travellers along the way
 But I know Lord that you are with me
 Encouraging, strengthening, calling me onwards.
 Give me patience, courage & the assurance that whatever happens
 You will continue to hold me in the palm of your hand.

Jenny Charlesworth
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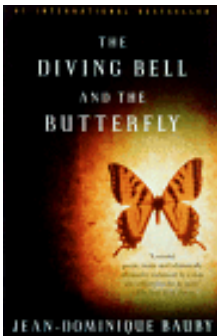


A Disability isn't always a Visibility!

Review Review Review

THE DIVING BELL AND THE BUTTERFLY

JEAN-DOMINIQUE BAUBY



HarperCollins Publishers
London, 2002
softcover \$22.99

available through all good bookstores
*book covers vary according to edition

THE BOOK

This remarkable auto-biography tells the story of Jean-Dominique Bauby, editor-in-chief of French fashion magazine *Elle*, and father of two young children.

At the age of 43 he suffered a massive stroke which leaves him totally paralysed, except for the capacity to flicker his left eye lid (as in a butterfly). His condition is called locked-in syndrome, and hence the image of being constrained inside an old-fashioned diving bell.

With the patient assistance of a hospital social worker he learns a method of communication that involves blinking with his functioning eye lid. From there he begins the painstaking task of transcribing, letter by letter, the words that would become this book.

Not only does Bauby describe what it's like to live in hospital with this imprisoning condition, and the positive and negative ways that people respond to him, but we are privileged to be taken into the realm of his very active imagination, which serves as a rich form of escape from a body that has failed him.

Bauby died three days after his book was published.

THE FILM

This story was brought to cinemas here in Australia early this year. The film takes you inside Bauby's head. You see his life through his one functioning eye. We are given a vivid impression of the world he conjures up in his imagination.

Look out for this film on DVD. It's unforgettable.

A word for all who care: Bauby's story reminds all who seek to offer authentic love and care to people with disability that it is important to look not just to the disabling effect of a person's disability, but also to affirm those parts of their being that are still uncontained.

Bauby's body was disabled, but his mind and imagination remained free.

*a Prayer of
Thanksgiving
for the Gifts
of All*

Loving Creator,

*We thank you for all the mem-
bers of your creation,
rich & poor
black & white
nearby & far away
able-bodied & impaired.*

*Truly we are all your works of
art. Truly we are all created in
your image.*

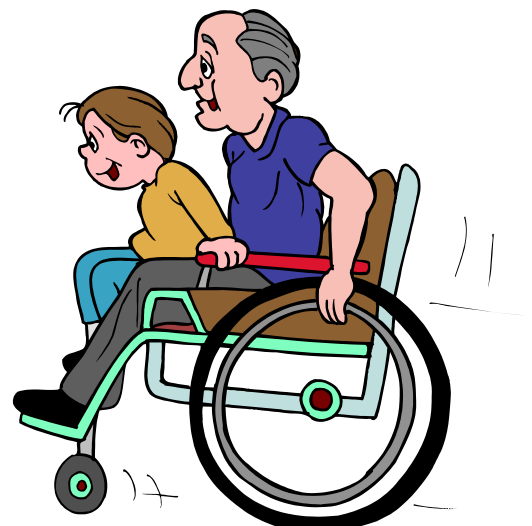
*Help each one of us to look into
the depth of ourselves and believe
in what we see—for we are the
work of your hands, gifted and
marvellously made.*

*As we come to believe in what
we see, so may we rejoice in what
we are.*

We are precious in your sight.

*Loving God, bless us now and con-
tinue to create us in your image.*

Amen.



All about my mother

Amy Willesee

THE AGE newspaper, Feb.16, 2008
Good Weekend section, pp.36-39

Amy Willesee, tells the story of her mother Carol Willesee a bright, bubbly actress and mother of three daughters who, at the age of 58, finds her body and mind suddenly and mysteriously starting to fall apart.

What began as a sustained ache in her legs quickly evolved into evermore debilitating symptoms, including difficulty walking and deteriorating eyesight. Even more disturbing was that she seemed to be becoming a different person. She became submissive and fearful, disconnected from those around her, not interested in wanting to hold her new grand-child. Her thoughts became jumbled, her words slurred, as she became confined to a wheelchair.

Specialists thought she had acquired some form of mental health condition, and was thus admitted to a private psychiatric hospital, causing Carol to fret.

With the feeling that no one in the medical profession cared Amy Googles her mother's symptoms and comes to the belief that Carol has Creutzfeldt-Jakob Disease (CJD), a rare degenerative brain disease, marked by rapidly progressive dementia, co-ordination difficulties and personality changes.

With Carol moved to a public hospital, and despite a lack of medical cooperation, Amy's diagnosis concerning CJD

is finally confirmed .

In the final days a move to a hospice brought a palliative care specialist who provided what Amy describes as a "soft landing." Appropriate medication allowed Carol's tension to ease. Her beauty returned. Remaining family time became filled with dancing and silliness, interspersed with tears. Until it was time to say good-bye.

"With his Santa Claus beard and honest voice, our palliative care specialist was our soft landing. He had a gentle touch when he acknowledged that Mum appeared to be in pain and distress. Why had no one else noticed?"

Amy Willesee

** if you would like your own copy of this story contact me at:
twhitney@sa.uca.org.au*

Leave your details and I'll forward you a hard copy.

FORUM

"Disability & the Local Church: Encouraging the Spirit of Hospitality"

On Friday June 13th at Highgate Park (formerly Julia Farr) an ecumenical forum was organised by the SACC Task Group on Disability Issues to discuss the issue of Disability and the Local Church.

Forty people from different denominations met to discuss either what they are doing in disability ministry in their local church and community, or what they would like to do, given appropriate support.

Many ideas and stories were shared. One very common concern was the need of people with disability to feel accepted by their local church.

Contact details of those attending the forum were collected and, once the Task Group has collated all the findings, participants will be contacted with a view to offering support and networking opportunities to local churches.

If you were unable to attend the forum but would like to find out more forward your contact details to: twhitney@sa.uca.org.au

Susan Laughs

by **Jeanne Willis & Tony Ross (ill.)**

published by Random House

London, 2001

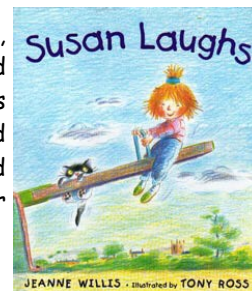
\$14.95

available all good bookstores
(cheaper 2nd hand through Amazon)

Ages: 4-8

Disability topic: physical disability
but no handicap

Susan laughs, sings, flies and swings. She has good and bad days, happy and sad days. Her feelings, fears, needs and



senses are the same as for me and you. The fact that she has a physical disability and gets around in a wheelchair doesn't make her different to any other child in terms of wants and needs, thoughts and feelings.

Written in poetic style, this thoughtful book reminds us to see a child with a physical disability as a child first before focussing on the wheelchair.

A book to be read by children, but a message to be understood by all.

Of a similar disability topic, and aimed at the same age group, is the following book, also available cheaply through Amazon.

Don't Call Me Special: A First Look at Disability

by **Pat Thomas & Lesley Harker (ill.)**

published by Barron's Educational

London, 2005

One of a series of children's books that also covers the themes of bullying, racism and death.