

NEWSLETTER

OCTOBER 2011 : ISSUE 100



enhanced
lifestyles

Happy
Birthday

Roshan Bantupalli Victoria Tregilgas
Kerry Wynn Carol Kooyman
Zoe Kitto Sarah Murray
Sharon Biddle Anne Lindsay
Trace Shelton Dean Slade

*all celebrate their birthdays
in October*

happiness

**'Being happy doesn't mean
that everything is perfect.
It means that you've decided to
look beyond the imperfections.'**
Mary Angelou



**PERSONAL ATTENDANT COFFEE MORNING
TUESDAY, 1ST NOVEMBER AT 1130AM**

This is a great opportunity to meet your co-workers and get to know the Enhanced Lifestyles support staff. If you would like to come to the Personal Attendant Coffee Morning please RSVP on 8363 4477.

69A PORTRUSH ROAD, PAYNEHAM

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Government funding gives people with disability international representation

*Media Release - Human Rights
and Equal Opportunity Commission - 28/9/11*

People with disability and their representatives will share in \$300,000 in Australian Government funding over three years to attend key international forums on human rights.

The Parliamentary Secretary for Disabilities and Carers, Senator Jan McLucas, announced today that grants will be available to successful applicants to attend conferences in an effort to ensure people with disability and the organisations representing them would have their say on the international stage. "This funding, under our National Disability Strategy, will support delegations representing peak disability and advocacy organisations to better represent the needs of people with disability internationally," Senator McLucas said.

Disability Discrimination Commissioner, Graeme Innes said, he was pleased to join in announcing the commencement of the funding program to support participation by people with disability in Australia and their organisations in key international processes and events on human rights. "The process of developing the Convention on the Rights of Persons with Disabilities showed how much could be achieved by governments and organisations representing people with disability from around the world working together in genuine partnership," Commissioner Innes said.

"I'm proud that Australia took the lead in involving people with disability in negotiating the Convention, and I warmly welcome this initiative to take that same level of involvement and partnership forward in making human rights a reality for people with disability here and around the world."

Senator McLucas said the grants, to be administered by the Australian Human Rights Commission, would give disability advocates the opportunity to use their experience and expertise to help inform and shape policies and programs affecting people with disability, their families and carers throughout the world.

[View details on this new initiative including eligibility on the Australian Human Rights Commission's website](#)

DIRC

HALLOWEEN CLUB COOL
A special event for people with a disability

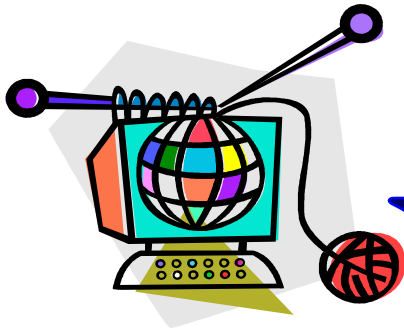
WEEKEND WARRIORS
LIVE YOUR ROCK DREAM

SPECTATION

THE GOV
BEST LIVE

When: Sunday 16 October 2011
Where: 12pm- 3pm @ THE GOV
59 Port Rd Hindmarsh SA
Entry: GOLD COIN DONATION

Proudly supported by the Governor Hindmarsh, Weekend Warriors and Tracey Korsten, Spectation. Thank you for your support and commitment!



ENHANCED LIFESTYLES' WEBSITE

The Enhanced Lifestyles' website is up and running. If you feel that you would like to see more on there, or have something that you would like to share with other consumers or Personal Attendants, please feel free to send the information in to info@enhancedlifestyles.com.au or post it into PO Box 294, Marden SA 5070.

Let us know what you think and if you would like to add something, that would be great.

Thanks

MANUAL HANDLING

A letter went out to all Personal Attendants in relation to Manual Handling Training. Please advise if you have done Manual Handling training with another agency recently and forward a copy of your certificate so we can update our records.

We are looking to organize training in November and will advise you accordingly. If you have any questions please contact the office.

PAGER USE

The pager is for emergencies only not general shift covering. Please ensure you leave a return phone number so the on call person can confirm who, what, where and when.

PLEASE ALSO NOTE you can only contact the paging service on 8305 2544. **DO NOT CALL THE MOBILE PHONE NUMBER DIRECT** as this may result in a shift not being filled.

Thank you

NDIS ... A WONDERFUL

Media Release - Disability Speaks - 2/9/11

Those reading the Productivity Commission report will be massively encouraged by the strong recommendations confirmed within e.g. page 3 (Overview and Recommendations) “ people will have much more choice..... people could cash out their funding allocation and direct the funding to areas of need” and page 25 “The commission has raised the possibility of an entirely new model of housing for people... people can then decide where they might live and what type of dwelling they might like” .

Such a visionary approach should not only be applauded but delivered as quickly as possible. NDIS cannot come soon enough. However giving genuine consumer driven choice is causing concern amongst some academics and advocacy groups. Could NDIS be about to take their power away?

For decades disability services have sadly been delivered in a divisive manner. This approach has caused massive division across the disability sector as consumers have felt their expectations cast aside often on the basis of academic theory and debateable research. Many experts have made a very good living peddling their ideas onto others. Some who think they know best seem to define their self worth by unflinchingly forcing their views. Consumers who disagree are quickly labelled as uneducated or ignorant. The big question remains “If the experts are correct why are their recommendations often so unpopular with so many rank and file consumers”?

While research will always remain important it's importance must always be diluted against the individual wishes of each and every disability consumer. In the disability sector the right to widespread options and complete choice must be legislated. No option can be off the table. Using euphemisms like “evidence based services as a basis for service standards” denigrates the personal needs, wishes and wants of too many consumers. Evidence has been impossible to correlate on new service models, the implementation of which has been previously stifled by lack of flexibility and choice. No one should be forced to bury their dream.

The release of the United Nations Convention on Disability has complicated the debate. While the United Nations convention enshrines the right to choose some have made choice the most abused word in the disability sector. While adopting slogans and logos aligned with choice the underlying message remains contradictory, people can choose providing they choose the traditional models experts and academics have championed for decades.

Some major advocacy groups are serial offenders. They have mostly been around for years, have the ear of government, often with the same leaders and policy makers and often lacking the genuine breadth of sector representation that will give comfort to those who the organizations purport to represent. Such advocates care little for the wishes , hopes and dreams of disability consumers and while disrespecting those with lived experience, propagate programs that treat people with a disability as if they are pumpkins.

CONTINUE ...

NEW ERA

The current "Shut In" campaign (www.shutin.org.au) is an example. Based on old fashioned and broad ranging assumptions (one size fits all) under the guise of attacking bogeyman institutions (Those horrible places that we all think should be shut) the reality is this program potentially attacks choice and worse still may stop the entrepreneurial design of future service models that will significantly increase flexibility, generate improved social interaction and enhance consumer and family management or lifestyle.

As an example any one reading the bizarre SACID productivity commission submission http://uat.pc.gov.au/_data/assets/pdf_file/0009/99279/sub0046.pdf would be confused by rhetoric that champions self managed funding but only if spent in certain ways. Such contradiction defies logic and borders on nonsense and cannot go unchallenged.

The release of the NDIS Productivity Commission report has created an explosion of posturing and self justification as some embark on a concerted campaign to make sure their perspective of how disability services should be delivered are enshrined in any future NDIS legislation. The federal government must ignore this last gasp stand. Consumers have spoken strongly via the commission inquiry.

For the last decade governments both state and federal have been besieged by consumers and their families angry with being told how to live and who they will receive services from. The government must ensure that choice is not hijacked by the vocal but is enshrined for all in future legislation as a fundamental right. In 2006 when the South Australia Government ignored the experts and as part of a pre election deal with D4D the South Australian political party ran a series of public meetings specifically on housing they were overwhelmed by alternative responses and subsequently rewrote to the chagrin of traditionalists the South Australia strategic Plan. If one consumer disagrees with many they are still entitled to their choice.

In time current service recommendations will be surpassed by a wave of consumer driven models, many yet to be dreamed up or implemented. Over time when these new models are academically evaluated the success will be visible to all but the hardened sceptics and yesterdays best practise will be tomorrows fish and chip wrapper. If you want to see something sensational give tens of thousands of people with a disability the financial support and the opportunity to create something special for themselves, get out of the way and watch in awe. Only then will you really see what the disability sector is really capable of.

David Holst

Chair - Disability Speaks Steering Committee & Intellectual Disability Association of South Australia (IDASA) - www.disabilityspeaks.com.au

**"To the world you may be one person,
but to ONE person you may be the WORLD"**



ANNUAL GENERAL MEETING

All consumers are advised the Annual General Meeting of Enhanced Lifestyles will be held on Monday 5th December 2011.

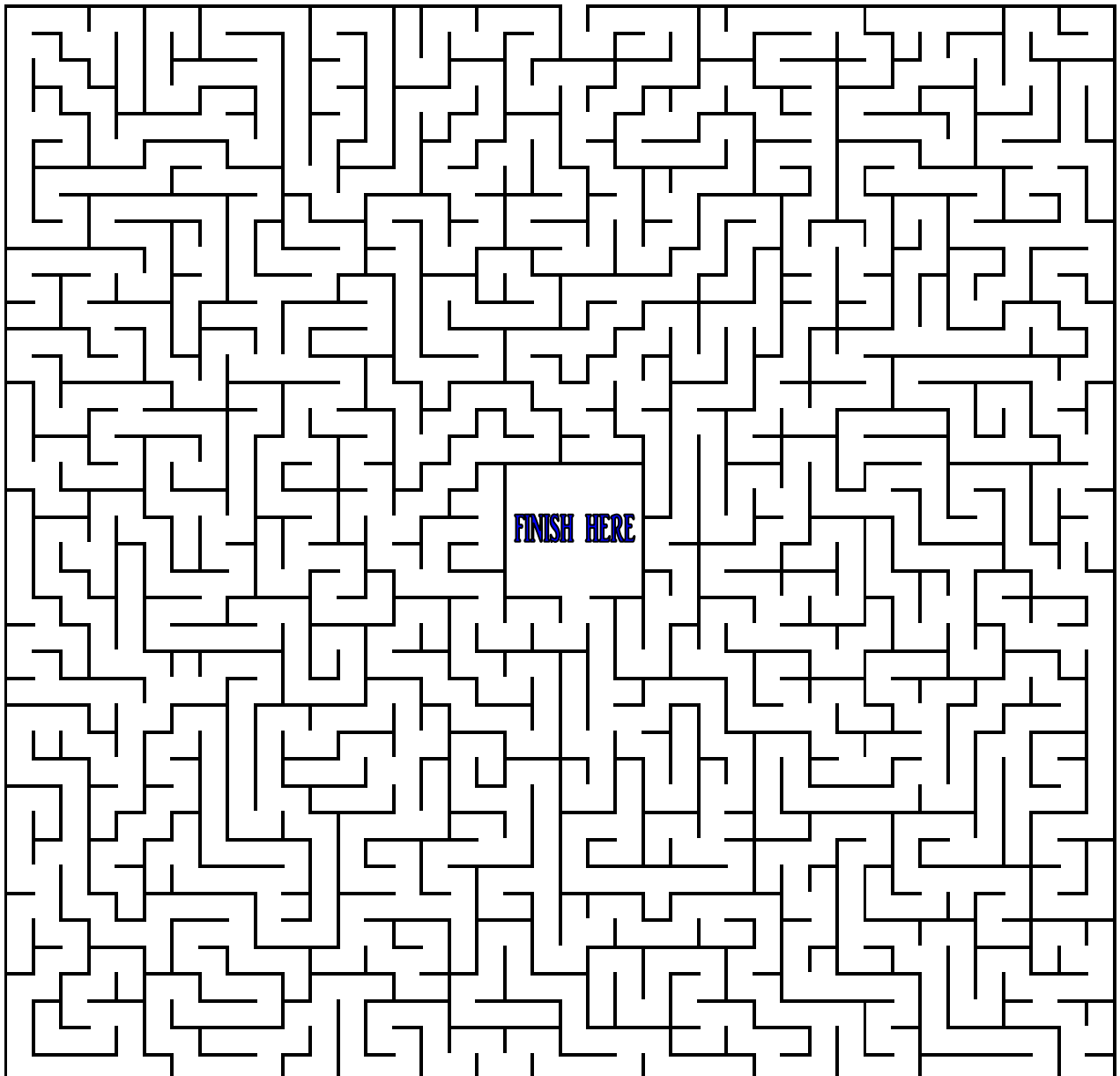
The meeting will commence at 6.00pm.

All are invited to attend and food and drinks will be provided at the conclusion of the meeting.

Please notify the office on 8363 4477 of your intention to attend.

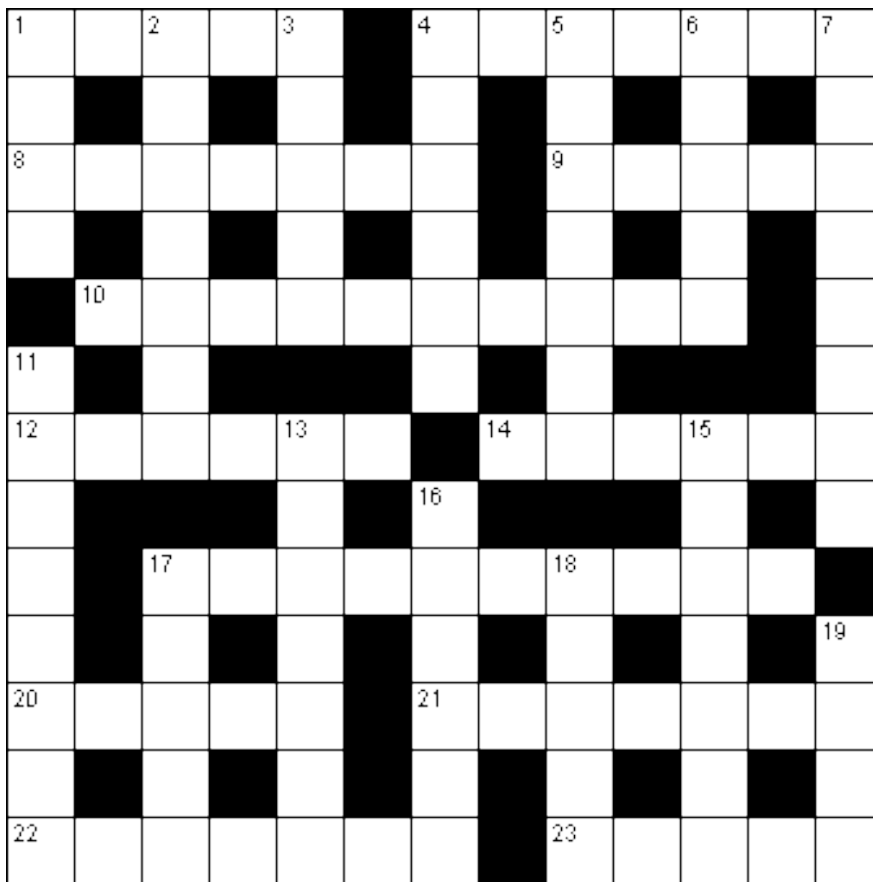
The meeting will be held at our offices
69A Portrush Road, Payneham

START HERE



TRUE OR FALSE CROSSWORD

There are two clues for each word. Can you work out which is true and which is false?



Down

1. Immense / Small (4)
2. Article of clothing / Wading bird (7)
3. Command / Request (5)
4. Placed in front of a word
/ Placed at the end of a word (6)
5. Flexible / Inflexible (7)
6. Pleased / Annoyed (5)
7. Large animal / Large insect (8)
11. Amaze / Bore (8)
13. Male chicken / Female chicken (7)
15. Skilled artist / Novice (7)
16. Often / Not often (6)
17. Dairy product / Vegetable (5)
18. Book of verse / Book of maps (5)
19. Border / Middle (4)

Across

1. Defined / Undefined (5)
4. Exact / Inexact (7)
8. Small fish / Large bird (7)
9. Part of the arm /
Part of the leg (5)
10. Limited / Unlimited (10)
12. Planet / Star (6)
14. Shrewdness /
Inexperience (6)
17. Works with / Works against (10)
20. Elegant / Awkward (5)
21. Concentrated /
Watered down (7)
22. Stimulating / Monotonous (7)
23. Push / Pull (5)

The Spoon Theory

by Christine Miserandino



My best friend and I were in the diner, talking. As usual, it was very late and we were eating French fries with gravy. Like normal girls our age, we spent a lot of time in the diner while in college, and most of the time we spent talking about boys, music or trivial things, that seemed very important at the time. We never got serious about anything in particular and spent most of our time laughing.

As I went to take some of my medicine with a snack as I usually did, she watched me with an awkward kind of stare, instead of continuing the conversation. She then asked me out of the blue what it felt like to have Lupus and be sick. I was shocked not only because she asked the random question, but also because I assumed she knew all there was to know about Lupus. She came to doctors with me, she saw me walk with a cane, and throw up in the bathroom. She had seen me cry in pain, what else was there to know?

I started to ramble on about pills, and aches and pains, but she kept pursuing, and didn't seem satisfied with my answers. I was a little surprised as being my roommate in college and friend for years; I thought she already knew the medical definition of Lupus. Then she looked at me with a face every sick person knows well, the face of pure curiosity about something no one healthy can truly understand. She asked what it felt like, not physically, but what it felt like to be me, to be sick.

As I tried to gain my composure, I glanced around the table for help or guidance, or at least stall for time to think. I was trying to find the right words. How do I answer a question I never was able to answer for myself? How do I explain every detail of every day being effected, and give the emotions a sick person goes through with clarity. I could have given up, cracked a joke like I usually do, and changed the subject, but I remember thinking if I don't try to explain this, how could I ever expect her to understand. If I can't explain this to my best friend, how could I explain my world to anyone else? I had to at least try.

At that moment, the spoon theory was born. I quickly grabbed every spoon on the table; hell I grabbed spoons off of the other tables. I looked at her in the eyes and said "Here you go, you have Lupus". She looked at me slightly confused, as anyone would when they are being handed a bouquet of spoons. The cold metal spoons clanked in my hands, as I grouped them together and shoved them into her hands. I explained that the difference in being sick and being healthy is having to make choices or to consciously think about things when the rest of the world doesn't have to. The healthy have the luxury of a life without choices, a gift most people take for granted.

Most people start the day with unlimited amount of possibilities, and energy to do whatever they desire, especially young people. For the most part, they do not need to worry about the effects of their actions. So for my explanation, I used spoons to convey this point. I wanted something for her to actually hold, for me to then take away, since most people who get sick feel a "loss" of a life they once knew. If I was in control of taking away the spoons, then she would know what it feels like to have someone or something else, in this case Lupus, being in control.

The Spoon Theory

She grabbed the spoons with excitement. She didn't understand what I was doing, but she is always up for a good time, so I guess she thought I was cracking a joke of some kind like I usually do when talking about touchy topics. Little did she know how serious I would become?



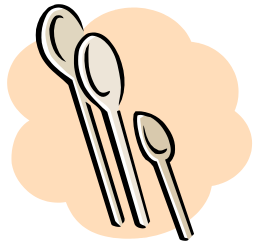
I asked her to count her spoons. She asked why, and I explained that when you are healthy you expect to have a never-ending supply of "spoons". But when you have to now plan your day, you need to know exactly how many "spoons" you are starting with. It doesn't guarantee that you might not lose some along the way, but at least it helps to know where you are starting. She counted out 12 spoons. She laughed and said she wanted more. I said no, and I knew right away that this little game would work, when she looked disappointed, and we hadn't even started yet. I've wanted more "spoons" for years and haven't found a way yet to get more, why should she? I also told her to always be conscious of how many she had, and not to drop them because she can never forget she has Lupus.

I asked her to list off the tasks of her day, including the most simple. As, she rattled off daily chores, or just fun things to do; I explained how each one would cost her a spoon. When she jumped right into getting ready for work as her first task of the morning, I cut her off and took away a spoon. I practically jumped down her throat. I said " No! You don't just get up. You have to crack open your eyes, and then realize you are late. You didn't sleep well the night before. You have to crawl out of bed, and then you have to make your self something to eat before you can do anything else, because if you don't, you can't take your medicine, and if you don't take your medicine you might as well give up all your spoons for today and tomorrow too." I quickly took away a spoon and she realized she hasn't even gotten dressed yet. Showering cost her spoon, just for washing her hair and shaving her legs. Reaching high and low that early in the morning could actually cost more than one spoon, but I figured I would give her a break; I didn't want to scare her right away. Getting dressed was worth another spoon. I stopped her and broke down every task to show her how every little detail needs to be thought about. You cannot simply just throw clothes on when you are sick. I explained that I have to see what clothes I can physically put on, if my hands hurt that day buttons are out of the question. If I have bruises that day, I need to wear long sleeves, and if I have a fever I need a sweater to stay warm and so on. If my hair is falling out I need to spend more time to look presentable, and then you need to factor in another 5 minutes for feeling badly that it took you 2 hours to do all this.



I think she was starting to understand when she theoretically didn't even get to work, and she was left with 6 spoons. I then explained to her that she needed to choose the rest of her day wisely, since when your "spoons" are gone, they are gone. Sometimes you can borrow against tomorrow's "spoons", but just think how hard tomorrow will be with less "spoons". I also needed to explain that a person who is sick always lives with the looming thought that tomorrow may be the day that a cold comes, or an infection, or any number of things that could be very dangerous. So you do not want to run low on "spoons", because you never know when you truly will need them. I didn't want to depress her, but I needed to be realistic, and unfortunately being prepared for the worst is part of a real day for me. We went through the rest of the day, and she slowly learned that skipping lunch would cost her a spoon, as well as standing on a train, or even typing at her computer too long. She was forced to make choices and think about things differently. Hypothetically, she had to choose not to run errands, so that she could eat dinner that night.

The Spoon Theory



When we got to the end of her pretend day, she said she was hungry. I summarized that she had to eat dinner but she only had one spoon left. If she cooked, she wouldn't have enough energy to clean the pots. If she went out for dinner, she might be too tired to drive home safely. Then I also explained, that I didn't even bother to add into this game, that she was so nauseous, that cooking was probably out of the question anyway. So she decided to make soup, it was easy. I then said it is only 7pm, you have the rest of the night but maybe end up with one spoon, so you can do something fun, or clean your apartment, or do chores, but you can't do it all.

I rarely see her emotional, so when I saw her upset I knew maybe I was getting through to her. I didn't want my friend to be upset, but at the same time I was happy to think finally maybe someone understood me a little bit. She had tears in her eyes and asked quietly "Christine, How do you do it? Do you really do this everyday?" I explained that some days were worse than others; some days I have more spoons than most. But I can never make it go away and I can't forget about it, I always have to think about it. I handed her a spoon I had been holding in reserve. I said simply, "I have learned to live life with an extra spoon in my pocket, in reserve. You need to always be prepared."

It's hard, the hardest thing I ever had to learn is to slow down, and not do everything. I fight this to this day. I hate feeling left out, having to choose to stay home, or to not get things done that I want to. I wanted her to feel that frustration. I wanted her to understand, that everything everyone else does comes so easy, but for me it is one hundred little jobs in one. I need to think about the weather, my temperature that day, and the whole day's plans before I can attack any one given thing. When other people can simply do things, I have to attack it and make a plan like I am strategizing a war. It is in that lifestyle, the difference between being sick and healthy. It is the beautiful ability to not think and just do. I miss that freedom. I miss never having to count "spoons".



After we were emotional and talked about this for a little while longer, I sensed she was sad. Maybe she finally understood. Maybe she realized that she never could truly and honestly say she understands. But at least now she might not complain so much when I can't go out for dinner some nights, or when I never seem to make it to her house and she always has to drive to mine. I gave her a hug when we walked out of the diner. I had the one spoon in my hand and I said "Don't worry. I see this as a blessing. I have been forced to think about everything I do. Do you know how many spoons people waste everyday? I don't have room for wasted time, or wasted "spoons" and I chose to spend this time with you."

Ever since this night, I have used the spoon theory to explain my life to many people. In fact, my family and friends refer to spoons all the time. It has been a code word for what I can and cannot do. Once people understand the spoon theory they seem to understand me better, but I also think they live their life a little differently too. I think it isn't just good for understanding Lupus, but anyone dealing with any disability or illness. Hopefully, they don't take so much for granted or their life in general. I give a piece of myself, in every sense of the word when I do anything. It has become an inside joke. I have become famous

Australian Institute of Health & Welfare Report - The use of health services among Australians with disability

30 September 2011

The Australian Institute of Health & Welfare has released a report, The use of health services among Australians with disability. This bulletin is the second in a series about health of people with disability. It examines the use of health services among Australians with disability based on national population health survey data.

View/download the report from the [Australian Institute of Health & Welfare website http://www.aihw.gov.au](http://www.aihw.gov.au)

NEWSLETTER

**We welcome any submissions
from consumers or staff.
Stories, events or photographs.
They can be submitted
electronically or we can scan
hardcopies. This is your
newsletter, lets hear about you.**

BOARD MEETING

The next Board Meeting will be held on Monday
7th November @ 5.30pm.
Members are advised they may attend any board meetings and submit items for the agenda 2 weeks prior to the meeting.
**Meetings are held on the first
Monday of the month.**



**"The healthiest part of a donut is the hole.
Unfortunately, you have to eat through
the rest of the donut to get there!"**



enhanced
lifestyles

Your Enhanced Lifestyles Representatives

Board of Management

Chairperson: Alan Bawden

Vice Chairperson: Trevor Harrison

Treasurer: Trudy McCoy

Secretary: Geoff Meyers

Committee: Jim Kidd , Helen Messner,
Jenny Meyers, Phillip Beddall and Lena Polo

Occupational Health & Safety Committee

Alan Bawden, Louise Braybon,
Helene Messner, Tammy Hunt,
Barbara Maegary and Chris Grilk