

Onguard!

A REGULAR NEWSLETTER FOR PRIVATE GUARDIANS IN NSW

SEPTEMBER 2006

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In this edition of Onguard! we are delighted to be able to share with you the stories of some current private guardians. At the PGSU we have daily contact with knowledgeable and resourceful private guardians working in difficult circumstances. Being a guardian is a serious and time consuming responsibility and when the going gets tough it can also be an isolating one. We hope these stories resonate with you and remind you that you're part of a community working to uphold the rights of people with disabilities.

Also in this edition you will find information about the Office of the Public Guardian's upcoming art exhibition, 'Tell us about yourself, tell us about your life', featuring works by people under guardianship. Have a look at the back page for more information about this exciting project.

Michael* has been a joint guardian for his sister Jennifer for eight years, since Jennifer acquired a brain injury in a car accident. Jennifer is a young woman but because of her high care needs she lives in a nursing home.

Looking back at the difficult situations I've faced as a guardian I wish I knew how hard it was going to be. I wish I had forewarning of the true culture of modern government agencies and aged care facilities. I did not expect active and repeated obstruction to our efforts to protect and recover an injured Australian. At worst I only expected indifference. In the end you just do your best. It is important as a guardian to focus on the positive difference you are able to make, rather than the extent you are unable to make the whole situation right.

The PGSU has helped with information and moral support. Working with the other joint guardians as a "family team" has helped to achieve positive outcomes for Jennifer. A team gives you other points of view and other angles to problem solve, moral support, and opportunity for time out without abandoning the person you are guardian for.

My tip for a newly appointed guardian is to take the time to learn what the role of a guardian is, and look at that role from the position of what you would want if you were the person you are guardian for. What would you want your guardian to do for you if you were in their shoes?

* Names and details have been changed

Helen has been a guardian to her 30 year old daughter Tracey for two years. Tracey has an intellectual disability.

As a young child Tracey was a happy and contented person, but when she was assaulted as a teenager she changed dramatically and was unable to stay at home. Since then, Tracey has had eight different accommodation placements in eight years, due to her disability and behaviour. At one stage Tracey ended up in a mental health unit for about six weeks. Although this was the most devastating time of my life, it also allowed me to be a strong advocate with DADHC to make sure Tracey received the assistance she needed.

Tracey now lives in a twenty-four hour supported group home with another young lady who has similar behaviour. This only occurred because I was fed up with what was happening and applied for and was granted legal guardianship. Before I became a guardian I felt no one would take any notice of what I was saying as a mother.

“Now I have the right to ask questions and demand that the right thing be done for my daughter”

I found it very difficult to accept that I had to be a legal guardian. I thought that being Tracey’s mother, knowing everything about her and always giving support to everyone should have been enough for people to listen. In the end I found that you need to be a legal guardian and find the inner strength to fight every battle you have to for the benefit of your daughter.

Just having to go and get legal guardianship to show people that I was serious about what happened to my daughter was a huge thing for me, but now I have the right to ask questions and demand (in the correct manner) that the right thing be done for the welfare of my daughter. No one will ever have the same emotional ties to my daughter that I have but they can still give her what she needs and I need to know that one day when I am not here to protect her that she is in a good place and happy. I had to be the strongest person and stand up for what is right to get my daughter where she is now.

You need to have commitment to the person and be able to look at things in a way that will benefit him or her, not you. Sometimes it is not easy to put your emotions aside but you really have to be focused on what is best for the person under guardianship and learn how to be effectively forceful to achieve what is right. Always know who is looking after the person under guardianship and ask questions all the time.

My wish for people with disabilities

My one wish would be that DADHC looked at the needs of each person and gave them a quality of life that they are entitled to, instead of just throwing people together even if they are not suited. - Helen

If I could have one wish granted for people with a disability I would ask for basic, no fault care. Every Australian deserves the right to basic care and a quality of life. No one should be left to suffer. - Michael

I wish that there was adequate provision of supported accommodation for young people with disabilities: quality respite accommodation and long term, permanent supported accommodation. Respite gives the family the opportunity to see that the young person can separate from them and survive. Options for permanent accommodation would allow planned transition from home to more independent living.

Families could participate in, and scrutinise the process, and at the same time offer support to their young adolescent. Many aged parents struggle to look after themselves, and spend their declining years anxious about the future of their disabled son/daughter, after they've gone. - Sarah

I have so many wishes for people with disabilities and the disability sector; greater equity and equality in the community, increased education and employment opportunities, better support services and assisted accommodation, it would be hard to single out just one.

I wish that we would never use the word disabled or disability. We all have abilities to a greater or lesser extent, why is one an ability whilst another is a disability?

If there was one single thing I could wish for it would be for greater compassion, understanding and acceptance across all age groups in our community. Young people can be very cruel and intolerant to those outside the mainstream peer network. Many older people are oblivious or blind to people with special needs, seemingly in denial, preferring someone else deals with the problem.

Perhaps if that wish was granted all the others would follow as a consequence including the abolition of the word 'disability'. - Tony

Sarah has been a guardian and financial manager to John, a young adult with an intellectual disability, for five years.

I got to know John as a young man and became his advocate. Following a crisis in John's family I applied for guardianship and was appointed by the Guardianship Tribunal. I saw this as an opportunity to help John make a new and better future for himself.

The first year of the guardianship order was busy, with health and psychological assessments, planning meetings with his carers, employer and the Department Ageing Disability & Home Care (DADHC), who organised accommodation.

For John it was an exciting yet confusing and challenging time, as he encountered experiences he'd never had in his life – meeting new people who were going to be part of his life, using the telephone, being consulted and included in many of the decisions being made and being given the opportunity to make choices. In short, being treated like any other young man with feelings, needs and rights.

“John is gaining confidence in making decisions and expressing opinions”

There have been many positive outcomes for John since the original order. He is happy and in good health and enjoys going to full time, paid work each day. He is gaining confidence in making decisions and in expressing opinions. It has been rewarding to see John enjoying his new found freedom. While he still has some way to go, I feel that his sense of empowerment means that there will be no turning back.

I've learned to be extremely diligent in keeping notes and in letter writing. If I'm dealing with any agencies (particularly government bureaucracies) I address my concerns to senior management and if need be to my local member or the relevant Minister. When all else fails I can lodge my concerns with the NSW Ombudsman. These steps have resulted in important decisions being made for John,

such as being given a guarantee that he would continue to reside in his home town and not be moved to an unfamiliar area; having psychological services restored when there were behaviour management issues to be addressed; and getting action plans and Occupational Health and Safety guidelines documented by the residential management.

“Show a willingness to consult and to collaborate and try to avoid a combative approach”

I learned quickly that addressing John's needs through the Functions was the easy part. Dealing with difficult family dynamics, unresolved disputes and anger proved to be a greater challenge.

I've worked hard at establishing the trust of John's carers and making clear to them what their duties and responsibilities are to John and to me, as his guardian. You can't always assume that this is known to service providers. I have found that many service providers are glad to have my involvement as a person with the legal authority to make decisions for John.

Show a willingness to consult and to collaborate and try to avoid a combative approach (try “we both have John's welfare at heart and we need to share in the resolution of the problem”). While there may be times when there's a need to consider a compromise, this should not impact on the integrity of the Order.

‘After the Hearing’ has become my Bible and has been an invaluable resource in setting out the principles by which a guardian's decisions are made. I have passed on a copy to John's carers and it has made the consultation and decision making process easier for them. The PGSU has been a great source of counsel. When in doubt or needing clarification, run issues past them before you act.

Initially I found putting everything in place time consuming, however, the workload eased after the first 12 months, and now, while I'm busy, we're having fun!

Tony has been a guardian to his son James for six months. James is a young adult with an intellectual disability and following an assault, Post Traumatic Stress Disorder.

After James was assaulted the resulting psychological and behavioural problems, combined with his underlying condition, made it impossible for him to cope in a family unit. When James went into government care, his mother and I felt that he was unable to make significant lifestyle and medical decisions for himself, and subsequently applied for a substitute decision maker to be appointed.

In hindsight there are always things we wish we had known before entering into significant commitments. At the time I made the decision to become James' guardian it was appropriate and in his best interests. I wanted the best possible outcome for James, and my decision was not influenced by what may or may not have lain ahead.

“I constantly ask myself, ‘Is this decision is my son’s best interest?’ ”

The ability to separate myself emotionally from James' situation has been helpful. I have to make decisions on James' behalf governed by clear and sensible thinking and judgement, based on reason rather than emotion or prejudice.

It's important to understand the role of a guardian as substitute decision maker. It would be impossible to be effective in the role if I didn't have a clear understanding of the responsibilities and my significance in James' life. It's like taking off the 'parent' hat and putting the 'guardian' hat on, in a manner of speaking.

Try to remain objective and emotionally detached otherwise your decisions may be affected. I constantly ask myself, “Is this decision in my son's best interest?”

Drawing upon the resources that are available to me as James' guardian has also helped. I recall being advised “don't try and do it alone”, but I automatically equate asking for help as failure. I can say that seeking assistance has made me a better and more effective guardian, and that means better outcomes for James.

The Private Guardian Support Unit has assisted me in defining my role and responsibilities, providing advice in relation to specific issues I was called upon to deal with, providing support in meetings with another government department, and if needed they were there to listen if it all got a bit overwhelming. They have a wealth of knowledge that simply would not otherwise be available to me.

Suffice to say after the above accolade, my very first tip would be to call the Private Guardian Support Unit. There is no shame in seeking help and given that nobody offers tuition in 'How to Be an Effective Guardian', it's your best option. Reading 'After the Hearing' is an absolute must and will get you off to a good start.

Don't become obsessed with whether you are making the right or wrong decisions. Chances are you will intuitively know what the right decision to make is, and there is good advice available to guide you if you utilise available support.

Lastly, and closely related to the last item, have a life beyond guardianship, it's not a twenty-four hour a day job. You need to maintain some balance in your life and devote time to other members of the family, work and leisure.

Tell us about yourself, tell us about your life

An OPG Art Project

The OPG art project 'tell us about yourself, tell us about your life' is underway and people under private guardianship are invited to participate. It is an opportunity to celebrate the talents of people under guardianship.

Guardians of artists are invited to contact the Information and Support Branch OPG if they wish to participate or know more about the project. OPG is aiming to hold the exhibition in early 2007 and guardians, artists, service providers and other interested persons will all be invited. OPG would prefer artwork such as paintings, drawings and prints, however, all artwork will be considered, including photographs and sculpture.

The Information and Support Branch of the OPG can be contacted on 02 9265 1443 or for country callers 1800 451 510 or informationandsupport@opg.nsw.gov.au