Carers news

Winter 2016

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Message from Caroline

Welcome to Carers News Winter edition.

With the roll out of the NDIS starting from 1 July 2016 across Victoria, we have focused this edition on NDIS Readiness. We have engaged with carers in the Barwon trial site and have learnt some 'readiness' lessons and tips from them which we'd like to share with you. It is estimated that by July 2019, 105,000 people will transition from their current provider into the NDIS in Victoria.

The premise of the NDIS is that it will provide opportunity for Australians with permanent and significant disability to receive the lifelong support they need to pursue their goals and participate in their communities. In addition, the greater choice and control offered by the NDIS will benefit people with disability and their carers and whilst we have heard some positive feedback from carers and participants, there remains many challenges to iron out.

During this transition period to a new scheme, it is inevitable that many carers (and the people they care for) are feeling some uncertainty. Carers Victoria's role in the roll out of the NDIS is to inform carers and the community about what we know and have learnt to date. We are sharing this information and knowledge, and working closely with carers in the Barwon area and with National Disability Insurance Agency (NDIA), as well as advocating for carers as part of the Ministerial NDIS Implementation Taskforce. In particular, we are asking for supports for carers which are separate to the supports provided to the person they care for, including:

- support to access and sustain employment
- carer specific supports, including respite, counselling and peer support
- education, training and skill development opportunities
- continuous involvement in NDIS planning processes, and
- support to understand the NDIS and the resulting changes to how carer and participant support is determined, provided and managed.

In our recent Information Roadshows across Victoria we provided specific information to carers about the NDIS rollout and provided carers with the opportunity to ask questions directly to the NDIA staff. These sessions provided valuable feedback to both the NDIA and Carers Victoria.

In this edition, you can also read about our Disability Support Organisation (DSO) project (page 17) and carers' experiences in the NDIS trial sites (page 8), and we have included articles on NDIS Readiness – planning and goal setting (page 6) and budgeting (page 12).

One more point I'd like to note - Carers News has changed to three editions per year from four. This change will enable us to reduce the increasing costs associated with printing and postage and use the savings to invest in continuing or expanding services to better assist carers.

Caroline Mulcahy
CEO, Carers Victoria

What's happening at Carers Victoria

LGBTI in the West Event

Carers Victoria in May celebrated LGBTI carers and people caring for LGBTI people at an evening event at the Williamstown Town Hall. This session also provided the opportunity to learn about inclusive support services available.

The event was supported by the City of Hobsons Bay and the Toyota Foundation as part of International Day Against Homophobia, Biphobia, Intersex Stigma and Transphobia (IDAHOT) on 17 May.

Information Roadshows

Our Information Roadshow sessions saw Carers Victoria in Shepparton, Ballarat, Horsham and Midura, with over 500 carers attending. At these sessions we provided information for carers on the NDIS, Aged Care Reforms and Consumer Directed Care. We also invited staff from the National Disability Insurance Agency (NDIA) to make presentations and answer carers' questions.

Voting is for Everyone Pilot Program – Carers Victoria and Victorian Electoral Commission (VEC)

In June Carers Victoria held the first pilot workshop session assisting those with disabilities to vote. Developed with the Victorian Electoral Commission (VEC), the program's aim is to improve carers' understanding of the options available to make voting easier for the person they care for.

Many people with a disability face particular challenges with aspects of the voting process. This workshop explores how carers can support someone with a disability to vote.

If you would like to host a VEC workshop or would like more information please call **1800 242 636** or email: **vec@carersvictoria.org.au**

Above // Left to Right: Toni Van Hamond, NDIA, Caroline Mulcahy, Carers Victoria, Greg Veal, Bendigo Bank, Kate Johnson, Carers Victoria, Ian Corcoran, Bendigo Bank at the Information Roadshow, Ballarat.

The Commissioner for Senior Victorians Visits Carers Victoria

Gerard Mansour, the Commissioner for Senior Victorians, recently visited Carers Victoria to provide a summary of his listening tour around Victoria, specifically looking at the insights he gained about the carer experience. The Commissioner gave an overview of the role of the Commissioner for Senior Victorians and responded to questions from carers who attended.

The Commissioner recently released a report. Endorsed by Carers Victoria '*Ageing is everyone's business: a report on social isolation and loneliness among senior Victorians*', the report calls for better state and local government planning, recognising the integral role of older people in achieving an age-friendly Victoria. The report commits to the ongoing involvement of older people, acknowledging the importance of partnerships between government, the community and the business sectors and agrees to work in partnership with the Victorian government and/or the Municipal Association of Victoria (MAV) to achieve an age-friendly Victoria.

You can read the full report at **www.seniorsonline.vic.gov.au/services-information/commissioner-for-senior-victorians/government-responsew-to%20ageing-is-everyones-business**

Carers Victoria Emergency Carer Kits

Carers Victoria has produced a new Carers Victoria Emergency Kit. These useful kits provide information on how to plan and be prepared for an emergency. Making an emergency plan gives you and the person you care for the reassurance there will be somebody to step in when needed, with clear instructions to guide them. Download the kit from **www.carersvictoria.org.au.**

Profile of a Regional Counsellor

Peter Hunt has been a counsellor in private practice in Mildura for over 16 years. He deals with a wide cross-section of areas involving individuals, couples, families, businesses, community groups and organisations, and sees clients from as far away as Broken Hill.

Above // Peter Hunt, Counsellor

Mildura is a relatively isolated region in Victoria's North West. Peter's family's farming background puts him in good stead with many of the clients he deals with. His four brothers are still farmers in the area.

Peter particularly enjoys working with individuals and couples who struggle to make sense of their predicament and he facilitates their way to more successful outcomes. His most challenging clients are children, who test his practice in ways others don't. Peter says his most rewarding clients come from Carers Victoria referrals. One of these was the mother of a boy with Asperger's Syndrome. Together they identified the boy was severely bullied at school, which led to him disengage with the system at the age of 12.

"I first saw the family in October last year when he was out of school. He couldn't return to school, and he couldn't get out of home. The family lives in Robinvale, so they would travel probably 110kms to get here each session. We talked about how we could get him back to school. We rang the school and talked about support for that."

The boy is back studying his VCE this year, which is a huge turnaround from last October when he wasn't in school at all.

"That's some of the real rich stuff, you know,' says Peter.

Peter and his wife Carolyn have four children of their own. The youngest child has an intellectual disability with extreme abusive behavioural outbreaks. Their two middle children are gay.

This diverse family life has given Peter much understanding of what his clients go through, which is important in a community where diversity may not be so visible.

Peter says that the greatest obstacle to wellbeing for regional carers is isolating themselves.

"By isolating yourself and not engaging in the community, you're getting depressed. That's why you need to engage in community.

> You need to gain some respite if that's the case, you need to put your hand up and say to me,' I can't cope with this, how can we move past it?"

That's the biggest hurdle, for clients to actually ask for help."

Carers Victoria's professional counsellors understand the various challenges facing carers. Counsellors are respectful, listen carefully and will focus on what is most important to you in your caring role.

For more information call **1800 242 636**.

The Best Time of our Lives

"It was the best time of our lives. We were in the best place, planning to go on our first cruise around the Pacific, dreaming of future trips on the Ghan through the centre of Australia.

We were having our bathroom remodelled for when we got old, and when maybe one of us needed a wheelchair or, was unable to cope in a 'normal' bathroom, we would be ready. But that was years away.

The builders were almost finished the bathroom when James had the first inkling of trouble. He is a diabetic and having his feet swell a little was not unusual, but the swelling continued. The builders finished and left on Monday.

On Wednesday he began to feel pain. When you have neuropathy (no feeling in your feet and legs) this is unusual, so we went to Emergency.

He was admitted to hospital and the feet continued to swell. They looked like two footballs on his feet. Thursday: the diagnosis – 'Charcot's Feet'. The heels were displaced. Double Charcot's (in both feet) is rare, but he had it.

He would be in plaster for 18 months, then fitted with Moon Boots. He was to be in a wheelchair, no weight bearing . Time would tell if he walked again. For now he would have plaster on his legs, to be changed every week those 18 months. I felt so much pain for me and him. I cried.

My wonderful 6ft 2 inch man now became shorter. He needed more help. He was very positive and took it all in his stride. I battled with sadness.

> Our cruise ship sailed without us. The Ghan keep on moving without us. Our lives for the next two years were doctors' appointments and weekly visits to the plaster clinic. We became good friends with people at the hospital. They felt like family.

The specialist was pleased he did not have to amputate either of his legs, as is often the case with this diagnosis. One of his success stories he told us. I like to think my prompt action when sores appeared, and my care and diligence are the reason for this happening.

Time has gone by with our lives changing greatly. It is almost seven years on and James is still in the wheelchair. He has some level of independence. He can catch an Ability Taxi to go to appointments alone. We go to the movies. We are blessed he has two legs, a keen mind and we have greater love for each other.

Above // Jenni and her husband James.

> I take care of his many needs. We like to be together and appreciate what we do have, each other.

Yes there are things we miss. A stand up hug, impromptu kisses. Travel is harder not impossible. There are things we don't like, but that is what tolerance and patience are about. Everyday together is a bonus and a blessing."

Jenni, Tasmania

Planning and Goal Setting for the NDIS

The National Disability Insurance Scheme (NDIS) planning and assessment process will help to determine the informal, community and mainstream services and any reasonable, necessary supports the person with disability may need to achieve their goals.

The planning and assessment process focuses on the person with a disability. It uses goal-based planning to consider the person's strengths. It also aims to maximise choice and independence.

It is important to work out existing supports and support needs to ensure any risks to NDIS participation are addressed and any additional kinds of support are identified.

As stated, the planning and assessment process focuses on the participant. It is the start of a lifelong relationship between them, yourself as their carer and the NDIS.

The NDIS focuses on people with disability, not carers. Carers cannot get their own NDIS individual support plan. However, many carers will benefit from the funded supports the person they care for obtains from the NDIS. For example, NDIS funded supports may help build the capacity of the person to become more independent, which may reduce the amount of care the carer needs to provide.

There are a range of supports available through the NDIS packages which may support carers in their caring role, either directly or indirectly.

What happens if the person I care for is not eligible for the NDIS?

If the National Disability Insurance Agency (NDIA) decided a person with disability is not eligible, NDIS funded supports will not be available to them or their carer. However, the person or their carer can still contact the NDIS to investigate other options.

Goal Setting

In the NDIS, goals are set in the Planning Process with the person with disability and you, their carer.

As a carer you can support the person to identify their goals, such as:

- Assist them to communicate their goals
- Help them identify what is important to them
- Provide support that puts the needs of the person with the disability first
- Support the person to make their own choices.

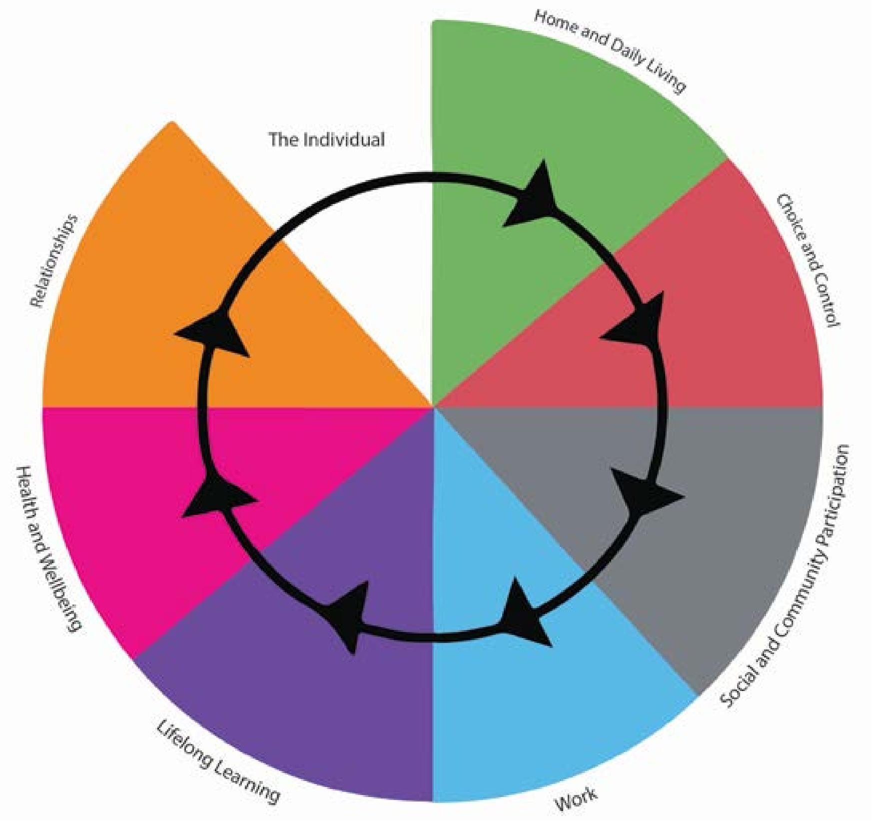
Goals give a clear direction and there is a sense of achievement once we reach our goals. It is important to remember goals can change as circumstances change.

Goal setting is a powerful process for thinking about the ideal future of the person you are caring for, and motivating them to turn this vision into reality.

The NDIS is being touted as the biggest reform since the introduction of Medicare. With so much attention on NDIS-readiness, we have invited the NDIA to write an article on the experiences of carers in the NDIS trial sites and the starting point for carers.

The 5 Step Planning Process

1. Understand the NDIS
2. Look at existing arrangements
3. Ask questions and explore different options e.g. what if things change?
4. Plan for change
5. Break down the steps to make it easier to navigate (including what resources you will need as a carer).



Experiences of Carers in the NDIS Trial Sites and the Starting Point for Carers

The transition to the full National Disability Insurance Scheme (NDIS) will mean an increase from 30,000 to an estimated 460,000 Australian participants under the age of 65 with a permanent and significant disability. There is no cap to the NDIS scheme.

From 1 July the NDIS will begin to roll out nationally in seven states and territories. In Western Australia, transition to the full scheme will commence from 1 July 2017, once an agreement is finalised between the Federal and Western Australian governments.

Carers SA Experience: Carers in the South Australian Trial Site[1]

The South Australian focus of the trial was on children and young people from birth to 14 years of age. In the first year (July 2013 – 30 June 2014), children from birth to five years of age who were already receiving services were the first recipients. Over a five-month period to June 2015 they spoke to 129 family carers from each region where Carers SA has a presence. Carers SA consulted with staff from regional offices, 20 disability service providers, the NDIA and professional service providers in rural and remote regions.

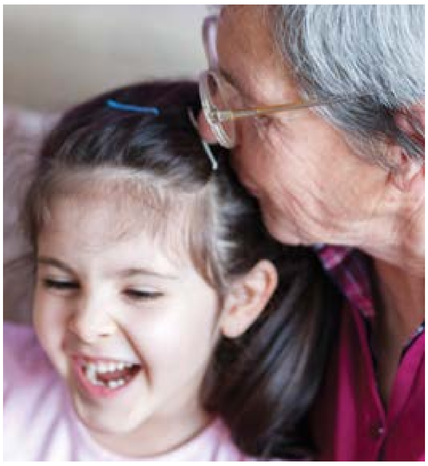
The level of satisfaction by family carers whose children already had a NDIS plan in place varied from very favourable to not meeting their child's needs adequately. While the therapy component of plans received the greatest level of approval, respite continued to be a major area of concern for most. Participants reported that the NDIA planners appeared to discount the importance of respite to family carers. Additionally, children who received respite via former State-funded arrangements found these were reduced under the NDIS.

> Many participants in rural and remote areas reflected their lack of knowledge translated into poorer NDIS plans for their children than their city counterparts.

Furthermore, this compounded their sense of failing to ensure their child's needs were adequately provided.

However, some carers said the planning was less arduous than their first experience of the NDIS and they had positive experiences with the planners. This was due to being better informed about the NDIS, familiar with the NDIS language and having gained confidence in working in the NDIS environment.

> "The NDIS is a blessing that changed our lives. We became the luckiest unlucky parents and we could start to live again as a family."



Sarah is four years old and lives with her grandmother who is her legal guardian. Sarah was born with a genetic abnormality which presents as an intellectual disability and a high degree of anxiety and confusion.

Before her NDIS plan eight months ago, Sarah was afraid of 'her own shadow' and was inconsolable if she was not in

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[1] Draws on The Carers NDIS Journey, Carers Australia Highlights and Hurdles report, Carers South Australia (December 2015).

easy reach of her grandmother. Her anxiety was so high she slept with her grandmother, as she was too afraid to be separated from her for even the smallest amount of time. Sarah was also prescribed medication for her anxiety.

Because of the support provided through the NDIS plan, Sarah's grandmother has learnt new coping strategies to manage her granddaughter's anxiety.

> Sarah now attends kindergarten twice a week, sleeps in her own bed most of the time and shopping is mostly no longer a challenging undertaking. Sarah's anti-anxiety medication has also been reduced.

Lucas is almost five years old and has had two NDIS planning reviews. His first plan was in August 2013, with a review in March 2014 and his most recent one was in May 2015. He has cerebral palsy and has been receiving physiotherapy and occupational and speech therapy since he was two years old.

> His therapists were very involved in supporting the family to develop his first two plans and no costs were imposed for this service by the therapist's employer.

During the development of the third plan, Lucas's mother requested additional information and supporting documentation from two of his therapists.

Recently she became aware that the organisation had invoiced the NDIS for these services against her child's plan. When she enquired why this had occurred she was told that all interactions between her and the therapists were now deemed 'billable hours'.

She was deeply concerned there had been no prior discussion about these changes and the amount of money she thought she had to use for her child's therapy was now reduced by $2,000.

She said that the lack of transparency about these new arrangements left her feeling let down by the organisation.

> "Had I known that this is what they were going to do I would have negotiated my son's plan differently."

Carers Victoria Experience: A carer in the Victorian Trial Site

Jenny lives and cares for her son Craig who is 40. Craig was diagnosed approximately eight years ago with severe depression, anxiety, OCD and agoraphobia. Craig has trouble going to places with lots of unknown people on his own. Jenny's other two sons live in Melbourne.

"When Barwon was selected as the Victorian NDIS trial site, I went to meetings about the Scheme. Craig was already with Transcend, a service provider for people with mental health issues. The NDIS contacted Craig when the trial began.

My experience in planning for supports with NDIS help has been pretty positive. I always attend with Craig and we usually have his support worker from Transcend. Having a support worker who has a professional understanding of the NDIS really helps me feel more comfortable. With his first plan, Craig was able to keep a dedicated support worker to help him.

I don't feel that the way the NDIS talks about permanent disability is negative for Craig's life. Because goals are the focus of the plan and Craig's goals are to be able to get back into society, like feeling comfortable in different situations outside of home with different people, the plan can help him achieve this.

> As Craig's mum with significant care responsibilities, I feel that other people have it worse than me. I do have lots of responsibility in my caring role.

I go to Craig's medical appointments such as going to see his psychiatrist, GP and podiatrist, as well as communicating with Centrelink.

I also attend workshops to learn more about mental illness. I go to two carer support groups; once a month we have education sessions with mental health professionals; and on Thursdays we do crafts together and we don't talk about our caring roles. But I know Craig's mental illness doesn't impact on me in the same way other carers are impacted. I can still leave Craig safe in the house.

I think it's important carers feel supported during the planning sessions, so they should think about bringing a third person along.

It's good to understand the NDIA may not offer everything, so participants should speak up about the supports they need. Remember, each person is different. The impact their illness has on their life will be different, so every plan will be different.

Craig has just completed his third NDIS plan and now there is provision for support workers to help him adjust to using public transport independently.

I do have choice and control in my life."

Jenny, carer

More Information

National Carers Advisory Line 1800 242 636

NDIS:	**www.ndis.gov.au** **1800 800 110**
Carers Australia:	**www.carersaustralia.com.au** **1800 242 636**
Carers Associations:	**www.carersvictoria.org.au** **www.carersact.org.au** **www.carerstas.org** **www.carers-sa.asn.au** **1800 242 636**
National Carer Gateway:	**www.carergateway.gov.au** **1800 422 737**

Starting Point For Carers

Get the big picture:
Think about the person's goals and interests. Talk to them and their support people about their future.

Get ready early:
It is important to start your transition planning as early as possible.

Get to know your options:
Research different areas and identify realistic options.

Get the skills:
Identify skills of the person with disability that they currently possess and how they can develop others.

Get organised:
Be organised and manage time effectively.

Get support:
Think about where the person can get support from and the types of additional support they may need.

Get involved:
There are many ways to gain experience that will be valuable in the future. Look at mainstream supports, as well as disability specific supports.

Be creative:
Think outside the box with regards to future needs.

Get confident:
Know their goals and help the person with disability to achieve them.

Budgeting

Step 1:

Track your day-to-day spending.

Often it is the everyday little expenses that end up costing you more over time. It's easy to lose track of $5 or $10.

Keep a diary. A spending diary can help you find out where your money is going by making a note of everything you spend for one pay period.

Understand your habits. The idea isn't to change your spending habits in the first phase. This is not about judging yourself, it's about knowing yourself better. By looking closely at your daily spending habits you will see your spending patterns and be able to make realistic choices about where you actually want your money to go.

How: Use a notebook and a pen or use apps like the Australian Securities and Investment Commission's free MoneySmart TrackMySPEND app.

Step 2:

Compare money in and money out.

Look at your incoming money and outgoing money. Think about where your money goes each month:

- Weekly basics – food, transport
- Regular bills – rent or mortgage, electricity, phone and insurance
- Other spending – clothes, holidays, car registration, medical expenses.

Do a budget. A budget is a simple tool to help you understand where your money goes in and out of your household.

It shows if you are spending more or less than you can afford. You can then take action to find the right balance between spending and saving.

How: Create a budget using your notebook or by using a spreadsheet or ASIC's MoneySmart's free budget planner, which you can use to input your information and then print it out.

Compare your income and expenses.

> Once you have done your budget, compare your income and expenses. How much money do you have to put towards your goals and lifestyle choices? Is your income higher or lower than your expenses?

I am spending more than my income. This is not the end of the world, but you need to take action to fix this. If you keep spending more than you can afford each month, you risk running into debt, which is easy to get into and harder to get out of.

Step 3:

Prioritise where you want your money to go

Reduce your expenses to an affordable level. Balance your budget by removing unnecessary items or what you could live without. If your debts are getting out of control and you are struggling to make ends meet, it is important to act quickly.

Refine your budget and direct your money to where it matters most. How does a budget work in practice? Using 'buckets' is a good way to sort out your money priorities.

Work out what you can afford for your wants. Divide up the rest of your money between your savings and spending.

Reduce your expenses. Highlight your needs and basic necessities in your budget. Then identify the things you want but could do without. List your savings and cuts – are they realistic? What are the most obvious ones to start with? Try not to cut out everything in your 'want' bucket. Allowing yourself a treat now and then will help you stick to your budget.

You can get free help with sorting out debts. A financial counsellor can help you get a clear picture of your situation, understand your options and work out a budget. You can also find a free financial counselling service on ASIC's MoneySmart website or by calling the National Financial Counselling Hotline 1800 007 007.

Set goals for the future. What are your possible goals? What is your top priority? How much will it cost? When would you like to achieve it? If you have borrowed money on a high interest rate, make paying off that debt your first priority, before taking on other goals. The savings goals calculator available from ASIC's MoneySmart website can help you work out how long it will take to reach your savings goals. You could also use their free TrackMyGOALS app to help you set and track progress towards your savings goals.

Put enough money from your 'income' bucket into your 'needs' bucket, i.e. the basic necessities you have to pay in order to live.

ASIC's MoneySmart website has lots of useful free fact sheets, calculators and tips.

www.moneysmart.gov.au Printed with permission by ASIC.

Step 4:

Act to make your money work for you

When you know what your budget looks like, take the final step and put it into action.

Make things as easy as possible for yourself by making things happen automatically. If you receive a regular payment from a salary or benefit on a particular day, set up a direct debit from your bank account for the day after to pay important bills.

If you are self-employed or have a variable income, you could work out your basic needs and divide that over a 12-month period into a 'basic needs' bucket. As your income fluctuates over the year, when you have more income put the extra amount above the basic needs into a savings account. You can then draw down from this account in leaner income months.

Keep your savings in a separate account with no ATM access. Save any extra pay rises, bonuses or tax refunds.

If you stick to your budget, you will gradually be able to achieve bigger goals like going on holiday.

National Disability Insurance Scheme – Rural and Remote Carers

There are more than two million Australians living in regional, rural and remote areas across Australia and more than 360,000 of these Australians are carers.

Carers without a disability are not the focus of the National Disability Insurance Scheme (NDIS); however, they will be expected to provide ongoing informal support for many participants. For the NDIS to succeed gaining the trust of carers and adequately supporting them to care sustainably into the future will therefore be essential.

The NDIS presents an opportunity for Australians with permanent and significant disability to receive the lifelong support they need to pursue their goals and participate in their communities. The greater choice and control offered by the NDIS promises not only to benefit people with disability, but also the family members and friends that provide informal support to people with disability, their carers.

The NDIS is designed to meet the needs of Australians with disability by creating a more flexible market in disability services. This means money for supports going directly to participants rather than block-funded service providers.

For rural and remote communities, this new system will present unique possibilities and challenges because existing health, education, transport and recreation services are often under-resourced.

> There is real concern that rural and remote communities may not present a 'viable' market for new or existing service providers to come to town. While disability supports are unlikely to appear immediately when the NDIS is rolled out in your town, the National Disability Insurance Agency (NDIA) assures the community that it will work with service providers, participants and families to encourage supports to take place in participants' communities.

Benefits to Carers

The support provided by the NDIS is already changing the lives of many carers for the better. Improved support for the participant often has a flow-on benefit for carers, reducing the emotional, physical and financial pressures of caring for many.

The NDIS benefits carers through:

- Significant improvements in the amount, quality, value and flexibility of support received by the NDIS participant after entering the scheme
- Flow-on benefits for carers, including the ability to return to work, reduced stress and less financial pressure
- Some funded supports directly supporting the caring role, including domestic assistance and family therapy, and
- Positive working relationships with NDIS planners.

Challenges to Carers

Many carers living in rural and remote areas are twice as likely to report having difficulty accessing services like doctors, telecommunications and government agencies than carers living in major cities. The cost associated with transport and accommodation is exceptionally high in remote areas.

> In addition, many have no or patchy internet access or no personal computer devices, and may therefore not be able to use the NDIA website.

Once a participant's plan is approved, he or she will no longer receive the mobility allowance payment. Plans will include some provision for the transport needed to access supports. This may include the cost of travelling to regional or metropolitan areas for medical appointments or other supports which are usually met by family carers. Think about this before you attend an NDIS planning meeting and ask if some or all of the cost can be met by the plan.

Understanding the NDIS

The uncertainty among carers appears to hinge on a lack of knowledge or misunderstanding of the principles behind the NDIS and how it works in practice.

Many carers in NSW[2] reported having difficulty understanding and engaging with the NDIS and supporting participants to prepare and implement their plans.

Carers within and outside the trial sites have had difficulty understanding the NDIS due to:

- Limited and inconsistent information (quality and consistency of information)
- Unclear language – the use of acronyms and jargon that make it difficult for many to understand
- Uncertainty about the Scheme roll out at the national level, and
- Inadequate communication with carers about what to expect.

Carer Recognition and Assessment
The NDIS policy framework recognises that:

- The role of carers in the life of the person they care for should be acknowledged and respected
- Planners should determine whether the informal support provided by carers is sustainable and reasonable, and
- Where appropriate, a plan should build the capacity of carers to provide support.

Issues identified have been:

- Varied treatment of carers by NDIS planners and some carers feeling their perspective has not been adequately taken into account, and
- A separate conversation between the planner and the carer is only a possibility, not a formal entitlement for carers.

Preparing and implementing the plan
Capacity-building initiatives have occurred, however:

- Not all carers are able to access these opportunities, many carers feel underprepared when they attend planning sessions
- Some carers feel that the NDIS has created more work for them, leaving them overwhelmed, and
- Many carers are finding NDIS plans difficult to read, understand and implement.

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[2] Draws on 'The NDIS one year in: Experiences of Carers in the Hunter Trial Site', A Carers NSW issues paper (September 2014).

Key Findings from '*The Carers NDIS Journey in South Australia, Highlights and Hurdles*' report (December 2015) included:

- Rural carers of children with disability reported to be less able to gain information and attend NDIS forums than their city counterparts
- Rural carers of children with disability voiced a greater level of uncertainty and anxiety when meeting with a NDIA planner and felt they were disadvantaged by their lack of knowledge and preparation for the planning meeting
- Rural carers of children with disability who had a NDIS plan in place voiced a higher degree of difficulty in accessing services and therapists in their local area
- Respite remained a high concern for the majority of carers of children with disability who have a NDIS plan and those waiting to meet with a NDIA planner, and
- 71% of carers whose children had a NDIS plan reported a lack of acknowledgement by the NDIS planners of the impact that the caring role has on them and is reportedly viewed by planners as not directly beneficial to the child, but rather only a benefit to the carer and therefore not a legitimate use of the NDIS funds.

Rural carers spoke frequently about their isolation and difficulty in accessing information, and the scarcity of services and supports in their areas. They expressed the challenge of having to travel long distances to attend information events relating to the NDIS.

> Rural carers reported a greater level of difficulty in accessing local services once their child's plan was approved.

This was either due to there being no services in their area or those that existed were fully booked. The waiting periods to access these were extensive. Also, the quality of local services was not of a high standard compared to metropolitan services, such as therapists. Another challenge due to remoteness is the recruitment and retention of staff, including allied health professionals.

Recommendations for Future Improvements

Key recommendations which would help rural and remote carers with the NDIS include:

- Improve and diversify information and communication, so they reach different sections of the population
- Increase carer engagement and consultation
- Offer all carers a separate conversation with the NDIS planner, and
- Improve capacity building and advocacy.

Reforms are moving forward towards a consumer-choice service, giving power to people in regards to choosing how they spend their money, and the planning and service providers they want.

> The Carer Associations will continue to advocate on behalf of the carers.

We will continue to advocate about what we believe should be covered in the NDIS for carers.

Where to Get Help

- Your local Carers Association **1800 242 636**.
- National Rural Health Alliance **www.ruralhealth.org.au** or **02 6285 4660**.
- Rural and Regional Health Australia **www.ruralhealthaustralia.gov.au** or **1800 020 103**.

More Information

Implementation of Disability Care Australia in Rural and Remote Areas, Roundtable Report, National Rural Health Alliance Inc., National Disability and Carer Alliance (February 2013).

Getting to Grips With The NDIS in Remote Areas, Bulletin from the public forum held in Mt Isa, National Rural Health Alliance Inc., National Disability and Carer Alliance (26 June 2014).

Carers Victoria's Disability *(DSO)* Support Organisation Project

Carers Victoria is one of 18 organisations Australia-wide that received funding to support 20 Local Peer Support Groups in their area to help people learn about and navigate the National Disability Insurance Scheme (NDIS). Carers Victoria has been working with Carer Support Groups to assist carers of people who may need assistance in making decisions; providing them with support for up to 12 months; education and training workshops; and facilitating a number of group sessions.

The project consists of:

- An information session about the NDIS
- 'Planning for the Future' – four free training workshop sessions on the NDIS, delivered by Carers Victoria's Education Services team
- Monthly support from the Carers Victoria DSO project officers for 12 months, and
- Information, tools and resources to help carers learn about the NDIS, including a workbook.

'The Planning for the Future' workshops assist carers to learn about navigating the NDIS. Workshops were created around 'Accommodation and Daily Living', 'Choice and Control', 'Lifelong Learning', 'Work, Social and Community Participation', and 'Relationships, Health and Wellbeing'. These are areas of life important to carers and people with disability and provide information to help them. These sessions give carers the opportunity to meet, discuss and explore the topics in more detail and to share their own experiences.

Carers Victoria has worked with existing Carer Support Groups and service providers to create networks of support. A series of workbooks have been produced to help carers prepare for the NDIS.

Carers Victoria hopes that by helping carers prepare for the NDIS, they can share planning skills and the 'empowering effect' can lead to better outcomes for people with disability and their carers.

"Excellent information. Feel a lot calmer about the planning process of NDIS."

"Very helpful and beneficial. I feel much more comfortable about NDIS now."

"Before I started I wondered why we needed so many sessions, but I can see now that there is a lot to become familiar with."

"Thank you for coming up to the regions/rural Victoria. This training is most important for all carers in Australia."

"Very informative and gives me a little more confidence to prepare when the rollout begins."

"Overall an informative program that has made me understand what is required of the carer and what my rights are when the NDIS rolls out."

"I feel much less overwhelmed."

"I finally feel like I understand what I need to do to prepare."

"If Carers Victoria is able to run other groups like this one, and you can possibly go, I would highly recommend you do."

For more information contact us on :
1800 242 636

Above // Carers attending a DSO session.

Easy quiche

INGREDIENTS

- Olive oil
- **4** slices wholegrain bread
- **250g** frozen spinach
- **1** brown onion, thinly sliced
- **400g** can mushrooms, drained
- **2** tomatoes, sliced
- **6** eggs
- **1 ½** cups milk
- **1** cup cheese, grated
- **1** tsp chilli powder
- Freshly ground or cracked black pepper.

METHOD

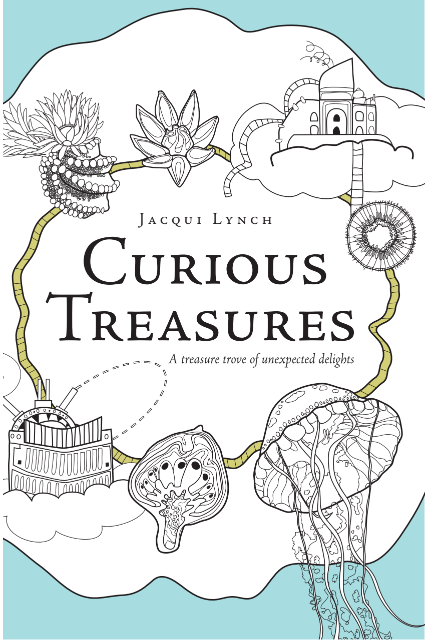
1. Preheat oven to 200°C (180°C fan forced).
2. Spray baking dish with oil.
3. Cut bread into halves.
4. Spread bread over base of a casserole dish.
5. Place spinach in microwave for 2 minutes or until defrosted.
6. Top bread with spinach, onion, mushrooms and tomatoes.
7. Beat the eggs, milk, cheese, paprika, and pepper.
8. Pour egg mixture over the bread and vegetables.
9. Bake for 30-35 minutes or until cooked through.
10. Serve warm.

Recipe reprinted permission by **www.livelighter.com.au**

Sudoku

9	1		8	6	5			
		4	2	7	9	1	6	5
	6		3				9	7
5	4		6				8	3
8		1		9		6		2
7	2		4					
	5		9	8	3		7	
	7		1	5	6	9	2	
6	9		7	4				1

9	1	7	8	6	5	2	3	4
3	8	4	2	7	9	1	6	5
2	6	5	3	1	4	8	9	7
5	4	9	6	2	1	7	8	3
8	3	1	5	9	7	6	4	2
7	2	6	4	3	8	5	1	9
1	5	2	9	8	3	4	7	6
4	7	3	1	5	6	9	2	8
6	9	8	7	4	2	3	5	1



Jacqui Lynch

Curious Treasures

A treasure trove of unexpected delights

Winners of 'Curious Treasure' Competition

Congratulations to the winners of our 'Curious Treasure' competition, Elaine Wilson and Laurence Harris from Tasmania.

'Curious Treasure' is a colouring book specifically created for carers by Jacqui Lynch. A treasure trove of unexpected delights; it is filled with 30 nature-based images to help carers relax and enter into a meditative mood while enjoying the growing popularity of colouring in.

More information:
www.curioustreasures.com.au
or call **03 5446 9792**
to purchase a downloadable copy of 'Curious Treasures' RRP **$20:00**, plus **$3.60** for postage.

The Victorian Office of Public Advocate

OPA Services

Office of the Public Advocate

The Victorian Office of Public Advocate (OPA) can advise carers about administration and guardianship, powers of attorney and medical consent. The OPA also deals with concerns regarding services for people with disabilities.

Since it's establishment in 1986, the OPA has promoted the rights, interests and dignity of people with disability (specifically intellectual impairment, mental illness, brain injury, physical disability or dementia) living in Victoria.

The Public Advocate, OPA staff and more than 900 volunteers provide guardianship and advocacy services for people with disability by:

- Acting as guardian when appointed by the Victorian Civil and Administrative Tribunal (VCAT) to make decisions in the best interests of a person with disability
- Providing advice, education and information to the public, as well as health, human services and legal professionals
- Undertaking research and strategic advocacy to improve laws, policies and the delivery of services that affect people with disability, and
- Supporting people with disability in interviews with Victoria Police and advocating for the rights of people living in group homes, supported accommodation or receiving treatment in a mental health facility.

Services

Volunteer Programs – Become a Volunteer

OPA's volunteers are from a variety of backgrounds. They work across four programs: Community Visitor Program; Independent Third Persons Program; the Community Guardianship Program, and the OVAL Project supported decision making program.

Volunteering for the OPA could be right for you if you:

- Are seeking a challenging and rewarding voluntary role
- Want to make a difference to a person with disability
- Want to stand up for the rights of people with disability
- Are comfortable talking to people with disability or mental illness
- Can commit to a few hours each week for at least two years as a volunteer (all OPA volunteer roles are long-term), with the exception of the OVAL Project which is a 12-month volunteering role
- Have good communication skills.

OPA provided advocacy for Gerry, a 54-year-old man with an intellectual disability, so he could participate in the pilot of the National Disability Insurance Scheme (NDIS). The OPA advocate met with Gerry, a staff member from his supported accommodation and a National Disability Insurance Agency planner.

With support from the OPA advocate, Gerry revealed he did not like some of the activities he was paying for and wanted to live alone, despite these issues not being reported in his personal plan. Gerry was able to have an NDIS plan developed which enabled him to try new activities and be considered for a move to new accommodation.

For more Information

www.publicadvocate.vic.gov.au
or call **1300 309 337**
9am – 5pm Monday to Friday

The quarterly magazine of Carers Victoria
Issue No 2 (Winter)

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Carers Victoria is supported by the Australian Government, Department of Social Services. Visit www.dss.gov.au for more information.

Carers Victoria acknowledges the support of the Victorian Government.

ARBN 143 579 257 Inc No. A0026274M

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Sign up for Voice, the Carers Victoria ebulletin, via our website: **www.carersvictoria.org.au/Voice**

Save the date

National Carers Week 2016

16 – 22 October

Australia counts on carers, can carers count on you?

Above // Carers and staff enjoying themselves at National Carers Week 2015.

National Carers Week is a time to recognise and celebrate the outstanding contribution that Australia's 2.8 million unpaid carers make to our nation. Anyone at any time can become a carer, and National Carers Week is an opportunity to raise community awareness among all Australians about the diversity of carers and their caring roles.

The key messages for Carers Week are:

- Creating Carer-Friendly Communities.
- Australia counts on carers. Let carers know they count.
- 36 million hours every week. That's how much we count on carers.
- Over $1 billion of unpaid care every week. That's how much we count on carers.
- Let carers know they count. Say thanks today.

For more information see **www.carersweek.com.au** and **www.carersvictoria.org.au**