

# STAND BY ME

Parkinson's NSW Inc Newsletter. Issue 113, Winter 2011  
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## UNITY WALK & FUN RUN 2011

[www.unitywalk.com.au](http://www.unitywalk.com.au)



**WHEN:** Sunday 28 August  
**WHERE:** Sydney Olympic Park  
Cathy Freeman Park  
(formerly The Overflow)

We have listened to your requests and the Parkinson's Unity Walk will be adding a Fun Run to this year's event.

On August 28, 2011, at Cathy Freeman Park, (formerly The Overflow) Sydney Olympic Park, participants will line up early in the morning for an 8km run, followed by the traditional Unity Walk of 2.4 or 4km with prizes for all age place getters in the run. The overall winning male and female runners will receive a return trip to Hawaii, including five nights accommodation at the Courtyard Marriott Waikiki Beach, courtesy of Hawaiian Airlines and Hawaii Tourism. The winners will also have the chance to compete in their choice of a similar event in Hawaii.

Following the run the traditional Unity Walk will take place, with the usual fun activities that have made the event so popular since it began four years ago; entertainment, children's rides, food and beverage, all encompassed by a great vibe.

Tell your family, friends, colleagues and running mates that the Parkinson's Unity Walk & Fun Run is the place to be on Sunday 28th August. Run and then use the Walk as a cool down. You can also create your own fundraising page and forward it to all your friends so you and/or your team are eligible for great prizes.

The new State Government is maintaining the tradition of its predecessor by providing free transport including Country Link travel to and from Sydney Olympic Park. Bendigo Bank is once again our Presenting Sponsor and we can't thank them enough for showing us that they are a true friend of the community of Parkinson's.

We look forward to welcoming you and all our current and new sponsors, at what will undoubtedly be the biggest and best Unity Walk ever.



Unity Walk supporters in 2010. Join with them this year on 28 August.



Proudly supported by  **Bendigo Bank**

**REGISTER:** Run registrations at the event from 7.30 am for 9.00am start.

**REGISTER:** Walk registrations at the event from 9.30am for 11.30 start.

For information on fundraising please call **1800 644 189**  
or register online at [www.unitywalk.com.au](http://www.unitywalk.com.au)

# From the **PRESIDENT**



Part of the strategy of dealing with Parkinson's is assuming control of the condition as best you can. As I meet more of our members in support groups and Parkinson's NSW (PNSW) functions, I am amazed to see how well many sufferers are managing to stay on top of what can often be such a cruel disease. Looking for common factors in their approach, I have noted four in particular:

**Knowledge** is vital, because PD is so variable. Understanding is changing daily, managing medication is intricate and empirical, and understanding what's happening is crucial. You can learn about PD through PNSW resources and services, from your peers in support groups and, importantly through the internet. I am disappointed we only have email addresses for about half our members, in an era when everyone should be connected. I would love to hear from members why you aren't online and if PNSW can help more people enjoy the benefits of email and the web. The successful Parkinson's person absorbs knowledge and understands their disease, as well as all the defences that can be thrown up to fight it.

**Working with your neurologist** is also a key factor in living well with PD — it's not good enough to be an occasional, passive participant in consultations. Your neurologist needs to know what's happening to you and how your meds are working and you are entitled to a clear explanation, from your neurologist, about what's happening to you; what you can expect and what you can do about it. Don't accept prescriptions blindly; give feedback about how drugs affect you. It's important to be honest about how you take your meds. If you are unhappy about how your treatment is going, compare notes with your peers and get a second opinion, rather than making changes alone.

**Active social engagement** is important for many of our members. They make an effort to take part in support group meetings, to get out and about and force PD into being part of their lives, but not the central feature. Coming out, so to speak, as a PD sufferer can be an issue, especially as symptoms begin to be more obvious. My own experience has been that being up front makes it easier for everyone, rather than hoping a tremor or slowness won't be noticed. PNSW can provide a framework of activities for an active social life, but don't neglect your circle of non-sufferer friends and family.

**Exercise** plays a key role for many PD sufferers, who find it makes them stronger to face off the condition, improves their mood as well as being a distraction from frustrating symptoms. The range of exercise is limitless and comes down to a choice of what you enjoy, what you can do and what's available. Cycling, walking, pilates, yoga, dancing, tai chi and Zumba are just a few activities that our members practice. I have heard of PD tailored exercise programs offered overseas, so I think we should investigate what we might be able to offer here. The message is don't give up, get out there and try out a range of exercise activities, until you find a combination that works for you. I hope that sharing members' strategies with you is helpful, and I also hope we can provide opportunities to maximise the benefit of those strategies for our members.

Please pass on ideas and comments, so PNSW can stay in touch with your needs and experiences.

**Chris Davis, President**

## Tiptoe through the tulips

We are thrilled that Parkinson's NSW is the charity of choice, selected by Southern Highlands Tourism, for this year's 51st Tulip Time Festival.

This event is one of the biggest festivals of its kind in Australia and we want to ensure that we repay the Tourism body's faith in us by helping present the best Tulip Time.

The Festival will run from 20 September to 3 October with traditional events like the Sydney to Bowral Bike Ride, Street Parade and Corbett Gardens Tulips in the Park display. We will hold our own fundraising events,

in collaboration with Southern Highlands Tourism, including the dinner dance, Countdown to Tulip Time, and the Tulip Time Festival of Golf. The Golf Festival will run over three consecutive days: a Corporate Day, Ladies Day and the John Daly Day social golf tournament.

A full calendar of events will be available soon, but be sure to put 20 September – 3 October in your diary, because there is nothing quite like the Southern Highlands in early springtime when the tulips bloom.

**Parkinson's NSW Inc.**  
ABN 93 023 603 545

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Lady Angela Carrick

# From the CEO



A quick look in the rear vision mirror. As I drive to I think of the tasks for that day, the month ahead, our plans and projects for the following months, including the many things we wish to achieve for people living with Parkinson's.

I have however been prompted to have a brief look in the rear vision mirror,

following the note of appreciation I received in the last *Stand by Me* on my completion of ten years with Parkinson's NSW Inc.

With the support of many dedicated volunteers including officers and members of Council, donors, trusts, companies, our staff and other supporters, much has changed over the last ten years.

When I started, the main service provided by the organisation was the InfoLine. This service continues as our front line service, now operated by staff professional including nurses and psychologists.

The backbone of the organisation, then and now, is our Support Groups, and these have now grown to over 65 across NSW. One important development over that period has been the development of assistance for our these groups, including the appointment of a Support Group Coordinator, teleconferences, meetings and materials to assist Support Group leaders.

Over the period we have introduced a specialised counselling service, recognising that Parkinson's can challenge individuals in many ways.

Education has been another key area of development. This has taken many forms. Firstly, we have introduced annual seminars for people living with Parkinson's so they can obtain first hand information from the experts in the field. In addition, we have had many more specific and regional seminars including Living Life with Parkinson's and Deep Brain Stimulation.

One of the most important areas of educational activity has involved providing seminars and material for others including: Allied health staff,

online education program for GPs and materials for residential care facilities.

Another important area of development has been raising awareness in the general community. From the grassroots level we introduced a speaker's program so we could train and support people living with Parkinson's to go out and talk to community organisations.

We have worked extensively with the media including providing and answering questions on topical issues. With pro bono assistance, we have prepared and arranged for community announcements in the media.

**In this and in many other areas dedicated professional advisory committees including researchers, clinicians, and allied health experts assist us.**

We have also worked both at State and Federal Government level, to increase services for people living with Parkinson's, and obtain greater support for our organisation. Last year for the first time we received funding, from the NSW Government, for three years. In addition, we have helped establish and manage a neurological nurse educator project in the NSW Shoalhaven area, with Commonwealth and private benefactor funding.

Another area of significant change over the decade has been the development of funding programs for research. We have taken care to introduce an equitable and transparent selection process. Grants are given following advice from external experts to ensure funds are directed to research most likely to be of benefit.

In this and in many other areas dedicated professional advisory committees including researchers, clinicians, and allied health experts assist us.

Funding for these various developments has come from a variety of sources, including, first and foremost, generous individuals who have left money to our organisation in their will.

We now have a bequest officer to assist with such donations. In addition, private foundations and trusts that have seen the merit in our proposals and submissions have significantly assisted our programs. Critically, there have been many individual donors including those through our fundraising events such as Unity Walk and golf days. Many companies, including those who provide pro bono work, have also assisted us.

Lastly and perhaps most importantly, have been the efforts of so many wonderful volunteers including Council Officers and members who have provided leadership and direction, and the many individuals who assist in our office, at special events, and with support groups. Now after a brief look in the rear vision mirror, it is back to the road ahead.

## **Apomine Nurse Support Service**

A national program of mobile, registered and Parkinson's disease trained nurses are available to assist with patient care and outcomes for patients prescribed Apomine. The contact number for the service is 1800 276 646.

## **Early onset research program**

One of our upcoming research projects is an enquiry into the specific needs of people diagnosed with Parkinson's under the age of 65. The NSW State Government is funding this project conducted in association with the University of Technology Sydney. We are seeking participation in online surveys. Any person diagnosed with Parkinson's under the age of 65 who is interested in participating in a focus group, should contact us so that we have a database of potential participants. email: [info@parkinsonsnsw.org.au](mailto:info@parkinsonsnsw.org.au)

Ethical standards will be met, including keeping personal details anonymous. We are hopeful that this project may lead to a better understanding of how to assist this particular group.

Yours in Parkinson's Friendship

**Miram Dixon, CEO**

# COPPER on the BRAIN

Katherine Scarpin is investigating why people with Parkinson's disease have low levels of copper in their brains.



When she started thinking about doctoral studies, Katherine Scarpin never imagined she would choose to study Parkinson's disease.

"My dad was diagnosed with Parkinson's disease when he was 48, about four years ago now. Dad's got early onset. Most people don't get Parkinson's until they are well into their 70s and 80s," she says.

"I thought I would never want to do Parkinson's research. I didn't think I wanted to be confronted with it every single day. But after a while, I started thinking, if I'm going to devote three years of my life to one project and really try to make a difference, I want it to be something special."

It's a challenge and I like that...

Katherine is now in her first year of a PhD with Assoc. Professor Kay Double at Neuroscience Research Australia.

Her project is focussing on why people with Parkinson's disease have low levels of copper in their brains.

"A lot of people are working on iron and alpha-synuclein [the protein that forms Lewy bodies in the brains of people with Parkinson's] but no one has looked at copper in Parkinson's before. It's a challenge and I like that about it."

Katherine's aim is to find out the consequences of low copper levels, and

to see what happens when they increase copper levels back to normal. We don't think low copper is the cause of Parkinson's, but we do think that low copper levels may be increasing the vulnerability of brain cells to dying," she says.

A new drug to treat Parkinson's?

The drugs that are currently used to treat Parkinson's disease work by replacing the dopamine that dying brain cells would normally produce. However, this only treats the symptoms. There are no drugs to slow down the rate at which those cells are dying.

"It's really sad when you realise what few options there are," says Katherine. "But if we're right about copper, then potentially this work could lead to the development

**"I thought I would never want to do Parkinson's research. I didn't think I wanted to be confronted with it every single day."**

of a drug that redistributes copper to where it's supposed to be. We might be able to slow down the rate of cell death and help people with Parkinson's live longer and have a better quality of life."

The thought of being able to help in some way helps Katherine through the challenges of a PhD.

"It's not easy and I have to be prepared for the fact that we might not find anything," she says. "But it's exciting to be involved in such a novel project."

As for her Dad, Katherine says he's doing exceptionally well.

"It's a pretty difficult thing to deal with but my Dad's pretty tough. I don't know whether what I'm doing now will help him specifically, but it could help people down the track like him. That makes me feel like I'm doing something really important with my life, something really meaningful."

## LIFETIME SUPPORT REWARDED

Congratulations to our recent Honorary Life Members: David Samer, David King and Julia Fry.

All three have demonstrated true humility in the way they support people living with Parkinson's. This dedication was recognised on World Parkinson's Day during the Life Membership Morning Tea at Tattersalls Club.

Thank you to the Hon. Victor Dominello MP, Member for Ryde who presented the awards.



L to R. Miriam Dixon, Hon. Victor Dominello MP, Julia Fry, David Samer, David King

## RESEARCH GRANTS



L to R. Serene Paul, Prof Sharon Naismith, Miriam Dixon, Dr Colleen Canning, Hon. Victor Dominello MP, Dr Scott Kim, Assoc Prof Kay Double

Four Research Grants were also awarded on World Parkinson's Day. We are grateful to the dedication of these people and the valuable research they are doing into Parkinson's Disease.

# ON the GROUP VINE

New groups in the North and Mid West give support for more people living with Parkinson's.

## North Arm Cove

In a corner of Port Stephens lies a group that started from Three Poets with Parkinson's, members of the local poetry group. On 7 March, ten people gathered in the local library to form the new support group called North Arm Cove.

Coalfields Support Group sent good wishes to this new group and Bruce King and Arthur Grebert from Manning/Great Lakes drove down to be part of their first meeting.

**North Arm Cove meets the 1st Monday of the month at 1.30pm.**  
**Leader, Edda Davis.**

## Lismore SG

Lismore SG was formed from a public meeting on 13 April. Thirty Four people came including Cathy Eggins from Grafton and Helen and Fred Boddington from Tweed Heads.

The Uniting Church hall was an excellent venue with a lift and inhouse catering from the Red Door Cafe.

Leader, Tony Betts, Occupational Therapist, Barry Briggs and Paul Aitken made a great team, assisting all. Dr Hugh Fairfull-Smith, Geriatrician, gave an excellent presentation on Parkinson's and Deborah England hosted an extensive Q&A session.

## Central Coast Young Onset

These members met on Thursday 12 May at the Elanora Hotel, East Gosford for coffee and lunch in the bistro. They plan to get together monthly on the Central Coast for a social meeting or outings, including walks and ferry rides. This will complement existing support groups in Niagara Park and San Remo.

**Next meeting. Ourimbah RSL**  
**Thursday 9 June, 11 am.**

**Contact Andrew O'Shea , 0423 358916**

## Mid Western support group

Mid Western support group was formed from a public meeting in Mudgee on Saturday 14 May. Clarrie Beckingham called the meeting after years of living with Parkinson's without seeking support. Twenty two people attended and formed a working committee.

## First meeting:

**Tuesday 14th June at 10am.**

**Contact Patricia Harvey 02 6373 3168**

## Teleconferences

Six telelinks were held over three days with 40 support groups taking part. Feedback was very positive showing groups are very active in promoting themselves, and raising awareness about Parkinson's.

Most groups enjoy social outings as well as formal meetings.

Groups were concerned about medications not available on the PBS and about the lack or loss of doctors in many areas.

## Narabri Unity Walk

Around the lake.

Everyone is welcome to walk and enjoy a sausage sizzle.

**When: Saturday 25 June at 10am.**

## Coalfields Support Group Seminar

**When: Friday 28 October**

**8:30am - 3:30pm**

East Maitland Bowling Club

Banks St, East Maitland

Cost: \$5 per person

**RSVP 5 September to Dee on**

**0428 310 112 or mail.cpsg@gmail.com**

## Joanne Brady wins Sole Encel Prize

Congratulations to Joanne Brady who was awarded the Sol Encel Prize by the University of NSW for *The best performance in a Year 4 Honours thesis in Sociology*, in the Bachelor of Arts or Bachelor of Social Science program. Her Honours thesis: *Ways of Interpreting a Parkinsonian Body*.



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# Recently DIAGNOSED

During February, PNSW hosted a program for people recently diagnosed with Parkinson's.

Over four consecutive Wednesday afternoons, it featured presentations by the Concord Parkinson's Clinic Allied Health Team. Participants received information and guidance on topics including Parkinson's medications, exercise and good diet and some non-motor aspects of Parkinson's. Participants had a chance to share their stories over afternoon tea with Parkinson's sufferers, partners and family members.

This opportunity to talk to others about adjusting to a diagnosis of Parkinson's is valuable and many have chosen to swap details and keep in contact.

PNSW and the Concord Allied Health Team is currently looking into the possibility of repeating the program with a new group for those people who remain on the waiting list from February.

## Follow up

On 23 May a reunion meeting was held, with participants sharing their experiences and useful information on their Parkinson's journey.

We are very pleased to confirm that, with the support of the Allied Health Team at Concord Clinic, this program will be repeated with a new group in October. If you have recently received a diagnosis of Parkinson's or commenced Parkinson's medications in late 2010 onwards and would like further details, please contact InfoLine on 1800 644 189.

## Best wishes & thank you



Medical student Natalie recently wed her long term boyfriend Zarko in Sydney. Instead of giving bonbonniere,

Natalie and Zarko decided to give a donation to Parkinson's NSW on behalf of their guests. Natalie is researching Parkinson's with Dr Lewis at BMRI and Prof Halliday & Dr Huang at NeuRA.

## True Inspiration

On the 20 May, Matt Caffrey, keen cyclist and supporter of PNSW put his fitness to the test.

Matt is living proof that with determination and a fighting spirit anything can be achieved! Through snow, ice and freezing temperatures Matt cycled 40.99km uphill from Jindabyne to Charlotte Pass in the Kosciusko National Park. He managed to climb a

whopping 1507m in elevation.

"Maintaining my fitness is incredibly important to me and I enjoy setting myself goals. Two years ago I tried to conquer this mountain but due to hazardous weather conditions was unable to complete it. I can definitely say I have ticked this off my bucket list," Matt is living proof that with determination and fighting spirit anything can be achieved!

Congratulations Matt. The Staff at PNSW are cheering you on for your next ride.



Matt and his bike on the road

## Scott Agent

"I choose to run the SMH half marathon to raise awareness and valuable research dollars for Parkinson's NSW as my father has been affected by the disease for over 30 years and it was close to my families heart.

It was a great goal to work towards in living a healthier lifestyle, less drinking, making better food choices and looking after my body. Both the fundraising and the actual running event were a tremendous success and PNSW congratulate you.

## My husband, Joe

*My Husband, Joe Brennan, was the type of man who could walk into a room and instantly lift the spirits of those in it. He had a tenacious fighting nature, I think this is why I loved and respected him so much.*

*Joe was diagnosed with Parkinson's disease in November, 2004. He also had arthritic knees which I presume was the result of his love for playing football, tennis, squash and golf. He struggled with the pain of osteoarthritis and the inconvenience of Parkinson's, yet I very rarely heard him complain, a testament to his strength of character.*

*He had a marvellous sense of humour and could always make me smile. He was a wonderful man and an inspiration to all who knew him. Joe always believed that it is what you do when faced with adversity that counts. He has passed this belief on to me. Joe faced his adversities head on with gusto and I know his family in Eire would have been proud of him, as I am.*

*Joe passed away on 20th January, 2011. He was 84. I won't lie, losing a loved one is never easy but I am hoping that by keeping his memory alive others will realise that they are not alone in their fight. There is a world of people out there who are facing the same thing as your "hardship".*

*I have made a commitment to Parkinson's NSW by donating money through my will towards helping others manage this disease.*

*This is our gift to you.*

*Leonie*

# From the COUNSELLING CORNER

In the last issue of *Stand By Me* I wrote about conflict. I mentioned that there are some strategies that may be useful in helping a person manage some of the feelings evoked by conflict.

If for instance, there has been an escalation of anger, something that often helps is to withdraw from the situation, if possible. To take some time to calm down and consider what has happened and what you want to do. It usually isn't helpful to retaliate or accuse, nor to insult or blame the other person.

I often talk to people about 'Teflon coating' themselves so that other people's unwanted comments or pronouncements can just 'slide off'. This way at a time of your own choosing, you can think about the comments and discard what is not helpful.

Try to relax, this will aid in turning off the 'fight or flight' response in your body and feelings of physical and mental calmness can begin to take hold. You may then like to consider what caused the problem and how it can be dealt with and hopefully resolved.

These thoughts aren't meant to be an exhaustive formula of how to manage conflict, but may give you some strategies to use.

Deb England

## A letter from Shoalhaven

It has been one year since I was appointed Shoalhaven Neurological Nurse and since then my career has taken a new and exciting path. For the first time in my nursing career I have taken up the challenge of community nursing. I have found my new colleagues to be incredibly resourceful in an area where resources are severely limited, as access to aged care services in rural and remote areas is often delayed and restricted.

For those of you who are not familiar with the Shoalhaven, it covers an area of 4660 square kilometres, stretching from Broughton (North of Berry) to North Durras (North of Batemans Bay) and comprises 49 towns and villages. The population in the region is around 100,000 with people over 60 making up over 20 percent of the residents. From its beautiful coastal towns to the amazing mountain views, local wineries and produce, it's a heavenly place to live.

I am supported by an amazing team, consisting of Parkinson's Australia, Parkinson's NSW and Dr Simon Lewis and his team at the Brain and Mind Research Institute. I am truly honoured and privileged to be part of this team.

The support of the Shoalhaven Neurological Nurse Project has been amazing, from the Community, local businesses, council members, health professionals, to people living with Parkinson's and their carers. I feel like I am

a part of the Parkinson's Community. As the majority of my work is done during home visits I would also like to acknowledge Bendigo Bank for their ongoing support of the project by supplying me with a car, an invaluable resource for this project.

My role as the neurological nurse educator is to assess people living with Parkinson's Disease (PD) and Parkinson's Plus conditions. I have a hands-on role with tasks such as overseeing medications and early identification of risks such as: falls, confusion, hallucinations and aspiration. Assessments at times can be challenging, sometimes causing tears when discussing some very personal issues but most of the time there are laughs. Discussing issues and problems surrounding every facet of PD and how to better manage them is a big part of my role.

My role also requires me to work closely with local GPs, neurologists and other health care professionals.

I am hoping that my presence as the Neurological Nurse Educator in Shoalhaven will continue to prove invaluable to patients, carers and health professionals and I am proud to be part of my new community team!

**Marilia Pereira**

Shoalhaven Neurological Nurse Educator



# WHAT'S ON

## June

20 First Steps Seminar

29 Coffee morning

## August

28 Unity Walk & Fun Run  
Sydney Olympic Park

## September Parkinson's Awareness Month

14 Parkinson's Seminar - Parliament House

15-16 Support Group Leaders Meeting

30 Coffee Morning

## Tulip Time

Bowral Southern Highlands

20 September - 3 October

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### For your local Support Group please call 1800 644 189

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[www.twitter.com/parkinsonsnsw](http://www.twitter.com/parkinsonsnsw)

### First Steps Seminar

Specifically for those diagnosed in the last 12 months. Hear from Dr Simon Lewis (neurologist) and information about the benefits of physiotherapy, exercise and PNSW support services.

When: Monday 20 June at 1.30pm for registration & tea/coffee

Seminar begins at 2pm

Brain Mind Research Institute, Level 5, 94 Mallet St, Camperdown.

To Register: Phone 1800 644 189 or (02) 8875 8900 by 16 June 2011

## Fundraising has its rewards

Karen and Andrew Whitton were the highest individual fundraisers in the Unity Walk 2010 and won a wonderful trip on the Indian Pacific.

"Thanks to Great Southern Rail for the opportunity to travel on the Indian Pacific. We had a fantastic time. The Nullarbor Green under water was an amazing sight!"

This year there are also some wonderful prizes to be won.

Our thanks go to this year's Unity Walk & Fun Run sponsors: Bendigo Bank, The Courtyard Marriott Wakiki Beach, Hawaiian Airlines and Hawaii Tourism.



Andrew Whitton "on the rails"



WAIKIKI BEACH

### In Memorium Donations 8 March - 24 May 2011

Marion Boyling	Antonina Pizzolato
Bill Coulter	Greta Ridler-Dutton
Eva Esterhay	Laura Rodley
Vivienne Green	Ken Ronan
John Higgins	Trevor Saunders
June Ison	George Stevenson
Angela Koutoulogenis	Phil Tavender
Walter Laidlaw	Nicholi Tokmakoff
Ken Lewis	James Webber
Mr Marshall	Paul Wood
Betty Nicholls	

### Celebration Donations

60th Wedding Anniversary  
Terry & Louise Zadro  
50th Wedding Anniversary  
Nigel and Mary Cattermole  
Retirement of Frank Clarke  
Birthday of the Late Allan Bible



Parkinson's NSW

The information provided is for guidance only and is not a substitute for professional medical advice. Parkinson's NSW Inc. takes reasonable care (in the context of freely available information) to keep the information it provides accurate and up-to-date; however, Parkinson's NSW does not guarantee the correctness and completeness of the information. You should confirm that the information is applicable to your circumstances by checking it with your doctor or a qualified health care professional.

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