

THE MULTIPLE SCLEROSIS SOCIETY OF TASMANIA

# Living with MS

Live fully, laugh often, love always

*A resource for couples living with MS*



**AUSTRALIA**  
Giving life back

**The Multiple Sclerosis  
Society of Tasmania is  
committed to enhancing  
the quality of life for  
people in Tasmania with  
MS and to reducing  
the impact upon their  
families and carers.**

This publication has been  
produced with the kind support  
of the Myer Community Fund  
and the Ian Potter Foundation.

**MS Helpline**



**1800 676 721**

**8.30am to 4.30pm Mon–Fri**



## Contents

Introduction to the Couples Project	4
MS and its Impact on Couples	6
Fatigue, MS and Couples	14
Sexuality and Intimacy	16
Communication—keeping the heart open	20
Gathering Support	24
Strategies for Coping	25
Further Helpful Reading and Resources	29
Final Word from the Couples	30
Information for Health Professionals	31

# Introduction and acknowledgements

In 2008/09, eight Tasmanian couples living with MS participated in **the Couples' Project: Live Fully, Laugh Often, Love Always**. The project included two weekends away, focus groups to gather information for this booklet, and ongoing support for the couples during after hours groups. This booklet contains the information gathered during the weekends and in focus groups.

It is designed as a resource for Couples Living with MS.

We would sincerely like to thank the Ian Potter Foundation, Myer Community Fund, Jonathan and Rick at Magnolia Cafe for providing their premises, food and atmosphere for the focus groups, Una from Eastcoaster Resort for whom nothing was too much trouble, Chris & Maryse Street for sharing their wisdom during the first weekend, Chris Street and Maureen Eadie with whom Sharon originally worked so closely to develop the original couples' program and our MS Society Tasmania colleagues for their enthusiasm and support for the project.

Finally, our most sincere thanks go to the eight couples involved in the project – each person contributed so much in making this project an overwhelming success.

Honesty, openness, tears and laughter featured so strongly during our time together and we have been incredibly privileged to be a part of this project.

**Sharon Wilkinson**  
Counsellor

**Lynsey Spaulding**  
Case Manager

# MS and its impact on couples



Here, the eight couples who participated in the pilot project answer questions put to them in focus group settings.

*Partner comments are marked with <sup>(P)</sup>*

# MS and its impact on couples

MS affects each individual differently. With the age of onset ranging from 20 – 50 years, MS affects people during their most productive years. Often referred to as the ‘uninvited guest’ MS arrives at the door and never goes home – affecting every relationship, every activity and every aspect of a couple’s life.

Feelings of loss with every new symptom and possible reduction of function are common, and the subsequent emotional impact is often overwhelming as couples and families try to cope with the uncertainty of change that can accompany MS. Partner caregivers face unique stressors and demands. Talking about and dealing with these challenges can be very difficult for many reasons, and the impact on a couple’s relationship can be huge.

*“ALL relationships have changed!”*

*“MS has completely changed relationships for me.”*

However, some couples have commented that there have been positive effects on their relationship with their partner as a result of a diagnosis of MS.

*“MS has made us appreciate what we have.”*

*“You make the best of a bad lot, you thank your lucky stars it’s not worse.”*

*“We actually have more time to be interested in the kid’s stuff – and we just appreciate the ‘small’ things.”*

# Inner Meaning

Living with MS has the capacity to affect the way couples feel about themselves, and can create a need for reordering personal values and attitudes in an effort to make sense of life changes. This may take time as couples learn to value other aspects of their lives and shift their priorities, recognising and accepting that their reality has changed.

## Couples' thoughts about attitudes and values:

*"Superficiality has decreased, and our real values have strengthened. You take what you get as part of a greater reality, not just for self-gratification." (P)*

*"I now value what is important and special in my life. It seems to have a new meaning, and I have the ability to live for, and appreciate the moment. Having to prioritise means that some things just aren't important anymore."*

*"My values have remained the same, but my attitude to planning and attention to detail has changed greatly. Flexibility is the key, live with disappointment but enjoy the good times." (P)*

*"I don't live with MS – it lives with me."*



# Managing constant change

One of the biggest features of MS is the constant change due to the unpredictability of symptoms and when and if they will occur. This often makes it difficult to plan ahead or make and keep commitments and can cause worry about the future. Loss of spontaneity and not being able to do things one used to do are common. As a result, the old life can come to an end, and sense of self can be disrupted due to the constant changes that can occur. Letting go of how life used to be and moving towards new ways of living are part of adjusting to change.

Managing the challenges of MS is greatly helped by the support and understanding of family and friends. Adopting a positive attitude and having realistic expectations of one's capacities are important in managing the constant change that may result from MS.

Clear and open communication as issues arise is vital.

## **These are the ways that some couples manage the issues around constant change and worries about the future:**

*"I've learnt that it's ok to rely on the help of others, especially the help of my mother-in-law."*

*"To me it's frustrating, time consuming and can play havoc with commitments, but we've learnt to understand each other a little more deeply and this has helped." (P)*

*"I think in general I'm a positive, cheerful easygoing person who loves life!! As a result I think these traits have helped. Mind you there are still days when this is not enough. I'm also open to new ideas and to learn new information – anything to help the journey run more smoothly!"*

*"We need to be flexible and spontaneous (within limits) and what has been helpful in our learning is understanding the unpredictable and multi-dimensional nature of the condition." (P)*

**When asked what they were proud of and what strengths they felt they have brought to the management of MS, couples said the following:**

*"We're proud of some little changes we've put in place. We also try and be honest with friends when things aren't going so well. I'm also proud of the way my partner constantly tries to understand, compromise, adjust, listen and learn."*

*"I'm proud of the way my partner has been my rock, and held my hand through every process even when I thought he didn't want to."*

*"Our faith, letting go, taking whatever comes and talking about it." <sup>(P)</sup>*

*"My positive attitude and stubbornness, also my wonderful family and friends who are there at the drop of a hat to give a helping hand."*





## Grief and Loss

Grief can be a normal emotional response to the losses and changes experienced as a result of living with MS. This is not only experienced by the person living with MS, but partners as well. The ongoing health of a relationship depends on the communication between partners of any issues that may arise.

Feelings can include loss of power and control, independence, identity, financial security and lifestyle. MS can force a redefinition of how couples see themselves as a result of these changes. Finding and adapting to new ways of working is important. Role changes within the family can occur, which require further adjustment to change, making communication within relationships even more crucial.

Feelings of grief and loss lessen over time as new ways of living are learned. Feelings of grief may be triggered at times and become raw again – but these feelings are usually only temporary. The focus needs to be on strengths, new possibilities and activities, and maintaining a positive attitude – and working on developing a meaningful life through engaging in enjoyable pursuits and relationships.

## When asked to talk about the losses they've experienced as a result of living with MS, couples said the following:

*"Spontaneity is gone – we can't live at a whim – not that you can with children – but children can adjust and love the 'drop of a hat' adventure – however with MS 'drop of a hat adventure' is long gone and I grieve it every day."*

*"I grieve the loss of impulsiveness, sometimes 'fun', the ability to do things as a family – either because of fatigue or environment (temperature). We have lost some ability to visit family regularly and travelling is now much trickier. Loss of spontaneity – we now need to plan."*

*"It took me a while to grieve the loss of my career. I think I am doing OK now with this. My life is into some sort of routine now, which leaves room and energy for new possibilities so who knows what will happen!"*

*"I feel I've lost someone to equally share responsibilities within the family. Unfortunately many things fall back into my lap (driving, transporting kids, arranging things at home at beginning and end of the day, homework, sorting out challenging relationship issues on bad MS days). There's not much opportunity to have 'me' time." <sup>(P)</sup>*

*"Unfortunately at times I feel we've lost each other due to the many challenges along the way, causing misunderstandings and communication breakdowns."*



## **Sense of Self**

Self and identity can be greatly affected by living with MS. Self is thought of as our personality and character, our core inner being. Our identity is how others see and think of us, a public face that we present. Through the experience of living with MS, self and identity go through an ongoing process of change and re-creation. Other aspects of self and identity will change, as physical health changes and varies. Changes in roles at home, at work, and socially mean that things that used to be ordinary are no longer. Other people might notice changes as well.

Eventually, a new perspective of self evolves as a result of changed circumstances and levels of ability. Shifts in self and identity have the potential to move from negative changes that may occur throughout the process, to positive changes. Letting go of past perceptions that no longer fit the current situation and changing ways of thinking and learning to value a new sense of self can support these shifts. This can help to remove any pressure that may be felt in trying to meet expectations of ourselves that are no longer possible.

## When asked how their identity had changed, and what had contributed to these changes, couples identified the following:

*"Learning to find ourselves individually – learning to love ourselves so we can share that love with each other."*

*"As a partner I have to take second place sometimes." (P)*

*"Identity – well it has completely changed! I saw myself as a professional career person – not anymore! My sense of self was changed when I lost my career. It was the worst day other than being diagnosed with MS."*

*"Some friendships have changed because we have less in common, I sometimes don't feel that unpaid home duties are viewed by many as important. Some degree of loss of independence has changed my identity too. I can't just head out, socialise, join groups etc, as it all revolves around MS. What if I'm too fatigued, can't drive, can't get home earlier etc?"*

The 'Transitions in Chronic Illness' series by Dr Debbie Kralik, Dr Anne van Loon, & Kerry Telford (2005) have been a guiding inspiration throughout the previous discussions, reproduced with the kind permission of Dr Debbie Kralik.

# Fatigue

Up to 80% of people with MS experience fatigue and it is commonly reported as the symptom that has the greatest impact on the life of people with MS and their partners. Fatigue was identified by all couples as having the biggest impact of all the symptoms. It is also common for people with MS to look 'well' despite feeling extremely tired, and friends and family may comment 'but you look so well!'. This can be an extreme source of frustration for the person with MS.

## When asked about the impact of fatigue and what they wanted others to know about it, couples said:

*"I would like others to know that fatigue can be debilitating, it's not always visibly obvious, it's unpredictable, it's sometimes overwhelming and can last for minutes, hours or days. IT IS NOT LAZINESS and can really impact on your state of mind if you let it!"*

*"Fatigue has a huge impact on each other, on social activities, relationships with children, friends, family and domestic stuff. IT IS HUGE!!!!!!!!!! I'm often too fatigued to chat, remember things, organise, or even think of what has to be done and where to start etc."*

*"I want others to understand the insidiousness of the fatigue that comes with MS."*

*"That the problem is mine though they need to have some understanding in times of fatigue. If I say NO I mean it!!"*

*"Fatigue impacts upon my relationship more than any other aspect of MS symptoms. I'm always tired, and my partner gets sick of me saying how tired I am and also of me having to go lie down a lot and then not feeling any better."*

*"Even my partner still doesn't understand, even after I sleep for two days, why I'm still so tired. When I'm tired, leave me alone because I get cranky and short tempered."*

Partners may find it hard to understand the severity and impact that fatigue has on a person with MS, despite best intentions. However, the impact of fatigue on the partner (and family and friends) of the person with MS can be huge.

### **Below are some comments from partners about fatigue:**

*"This is the biggest impact on family and relationships. It is so unpredictable, and can place a great deal of pressure on the partner as it can occur at the most inopportune time. This places pressure on the partner to change the best-laid plans, but more importantly, the partner that works can have pressure from the employer and family as well as the person with MS. This can be very demoralising at times and there's no script to get you through, just tread water and keep breathing!!!"* <sup>(P)</sup>

*"It is very hard to have others accurately know what the fatigue does and to what level. Most people just think the MS person is 'tired' as most people get. The solution is to be transparent with people and honestly describe what happens."* <sup>(P)</sup>

*"We need to watch out for overdoing things and we have no planning these days. We have to cope with the loss of spontaneity in all things."* <sup>(P)</sup>

*"Sometimes I hear myself saying things I wish I didn't say – if my partner doesn't do the things I expect when I get home from working all day and I'm tired. I'm working really hard to understand, to be patient and to communicate better."* <sup>(P)</sup>



## Sexuality and Intimacy

Although sexual difficulties can occur at any time in people's lives, MS may bring particular problems that can occur with both men and women. While not everyone will have sexual changes due to their MS, there are a number of factors that may affect a person's sexual function or sexuality. There may be interruptions to the messages sent between the brain and sexual organs via the spinal cord which can affect sexual arousal, response and orgasm. There may be the physical affects of fatigue, spasticity or pain, or psychosocial factors such as low mood or low self esteem that can affect feelings of desire and impact on the very essence of the sexual self.

People with MS and their partners often report that sexual difficulties can create both physical and emotional barriers and that their relationships are affected as a result. Talking about it, recognising that there is a problem and seeking medical advice and/or counselling support is a first step to ensuring problems are kept to a minimum.

## When asked how living with MS impacts on their sexual self, couples' responses were:

*"On a good day I feel little impact but on a bad day I tend to withdraw from any sexual activity. Therefore I have lost the spontaneity that I once had and that others without MS may have. The impact is big."*

*"We have to adapt to the changed circumstances and my partner has to be more considerate and understanding. We have accepted quality sex rather than quantity."*

*"To me I don't see myself any differently; however, my outlook on this area has had to go through a big change in terms of partner requirements and sensitivity. This will always be a big challenge and will need careful consideration in terms of partner and self needs. Be willing to experiment." <sup>(P)</sup>*



*"It impacts a great deal on how I see myself sexually. It completely changes the pace of things, how your body changes/responds/looks. Fatigue has a huge impact as when you are completely stuffed, it's not likely you will see yourself in a positive frame of mind."*

Dr Rosie King, in her book *“Good Loving Great Sex”* (1997) talks about sex being a continuum of bonding behaviours, with each step playing an integral part.

## Communication > Intimacy > Sensuality > Sexuality

The first step is communication: openly discussing the impact of MS on your sexuality. This means creating an atmosphere of acceptance and safety where talking about what works and doesn't work is OK. Being able to tell each other what used to give pleasure, but now causes pain, numbness or distress, or being free to talk about feelings and anxieties, without accusations or blame, can bring couples closer and help to dissolve fears.

Communicating and self disclosure lead to the development of emotional intimacy, where there is safety and trust enough to strip away the mask and share who you really are and how you really feel. Discussing sensitive issues can be very uncomfortable at first, but gets easier over time. It can be helpful to set aside some time on a regular basis that is devoted to discussing physical intimacy and closeness.

Exploring ways to heighten sensuality can delight the five senses – sight, sound, touch, smell and taste. Expressing affection and love in sensual ways might include massage with oils, music, relaxation, candles, soft lighting, eating and drinking, beautiful views...make a list of ways your sensuality might be enhanced and share with your partner.

This leads to sexuality, of which penetrative intercourse may play just a small part. Creativity and taking the pressure off helps as you broaden your sexual repertoire by exploring outercourse options. Sexual aids, good lubricant, erotic books and dvds, self exploration to find what is enjoyable and what causes discomfort, valuing the cuddles, hugs and strokes are all options that can keep you connected and help heighten sexual pleasure, with or without intercourse.

From *Good Loving Great Sex* by Dr Rosie King 1997.

## Strategies from couples to help deal with sexuality and intimacy:

*"Talking about it and being honest."*

*"Good lubricant!"*

*"Open communication in relation to needs, wants and what can actually be achieved – and a sense of adventure."*

*"Being sooooo sensitive to each other's needs, chatting about it, seeking outside support (counselling) and paramount – making SOME time together to enjoy each other's company. Also, it is important to experiment, just enjoy each other, perhaps less focused on SEX."*

*"Consider the other, sacrifice your desires at times, this can happen irrespective of MS." (P)*

*"We don't have any issues with sexuality as it hasn't affected us personally yet, but when it does we will deal with it as a couple or we will seek counselling."*





## **Open Communication... keeping the heart open**

The ability to communicate well is probably the most essential ingredient to the health of your relationship.

Clear communication in a relationship starts with each person being able to talk safely and openly about what is important. Lack of communication is widely recognised as one of the most pressing problems in a relationship, and the challenge of communicating well is increased with the onset of chronic illness such as MS.

Good communication involves talking clearly, listening carefully, and fully understanding each other. There are many tools to assist with effective communication. Taking personal responsibility; being honest; accepting each other's differences; becoming better listeners; using "I" messages; being generous and compassionate; being patient; being able to forgive; endeavouring to understand and 'walk a mile in each other's shoes'; and above all, keeping the heart open are all cornerstones of great communication within a healthy relationship.

## One special communication tool: The Five Love Languages *Dr Garry Chapman*

The need to feel loved is a basic human emotional need and is at the heart of most couple's desires. The emotional language that speaks love to one person may be as different for the partner as Chinese from English. Being willing to learn and speak a partner's primary love language is a powerful tool for being an effective communicator of love.

Dr Chapman writes that there are basically five emotional love languages, that is, five ways that people speak and understand emotional love:

1. Quality Time
2. Words of Affirmation
3. Gifts
4. Acts of Service
5. Physical Touch

Couples seldom have the same primary love language, and confusion starts when one love language is spoken, and the partner does not understand that this is in fact an expression of love. The message does not come through, because to them, it is a foreign language.

Love is a choice, and choosing to love and express love using the partner's primary love language has made a drastic difference in many relationships. When the emotional need for love is met, the climate is created for dealing productively with whatever life may bring and this can be of particular benefit to couples living with the challenges of MS.

Reproduced with the kind permission of Dr Gary Chapman, 'The Five Love Languages', 1992.

## Couples' thoughts after learning about the 5 Love Languages:

*"Learning about the five love languages helped me to understand my partner more."*

*"Learning about the love languages during the Couples Program has made the biggest difference to our lives. We have found out how important quality time is to us and spend more time talking. We now set aside time that's just for us – not always easy when there's children around!"*

*"I now recognise my own love language – and how well my partner speaks it to me."*

*"Knowing about the five love languages, understanding your own primary love language and then discovering the primary language of your partner is brilliant and will be one of the most important communication tools you will ever learn."*

## One last communication tip: Fighting Fair

Most couples live together, eat together, share the same house together, day in, day out. Often they care for each other and have high expectations as to how they wish to be treated by each other. Being human, couples may occasionally let each other down. Rather than ask how to avoid conflict, couples might ask how to avoid hurting each other or their relationship when there's an argument.

## Some tips for fair fighting:

- If possible, have some time out by taking a break to cool off. Discuss when the intensity has dropped.
- Stay on goal by dealing with one issue at a time – don't stack the argument with the last 10 years' disappointments.
- Be clear and beware of name calling, criticism or verbal abuse.
- Be aware of yourself and take responsibility for your part. You can choose to respond differently.
- Attack the problem not the person.
- Remain calm, stay in control, take deep breaths.
- Negotiate a time-out signal when there is intense anger – leave the situation until calmer.
- Choose your fights wisely – don't argue over little things.
- Humour helps – even during an argument.
- Be willing to be flexible – sometimes your feelings change.
- The aim of fighting is closeness – show appreciation when your partner understands your side. Clearing the air makes room for love.

## Some couples' comments about dealing with conflict:

*"When I started thinking about my emotions during our session I realised I was using anger to get what I wanted and our relationship was like adult /child. Now I'm more aware, I've started making some changes, like taking some responsibility and it has made a big difference."*

*"The speaker listener tool works a treat when we have to deal with the big stuff."*

The speaker listener technique is a tool for dealing with the big arguments or big issues from *Fighting for Your Marriage: Positive Steps for Preventing Divorce and Preserving a Lasting Love*, by HJ Markman, SM Stanley and SL Blumberg, (2001)

# Gathering Support

*"It's been helpful to learn from others in the same boat on how to cope."*

The value of finding support amongst other couples who are experiencing similar issues whilst living with MS is enormous. A support group is a group that involves people coming together in a supportive environment to share experiences, feelings and information, and to receive emotional support (Cancer Council NSW, 2006).

A group can provide a sense of belonging, so that group members feel they are not alone in their feelings and experiences. Often members will feel supported, cared for and accepted. Belonging to a group can also reduce feelings of isolation, due to having a sense of community. People feel connected with other members which improves coping skills.

Groups can also provide empathy, as members are heard and understood. People outside of a support group may not understand the unique

experience of couples living with MS. Within a group couples often feel safe to express their feelings and difficult emotions. Outside of the group feelings may be hidden to protect others. Humour is also a factor in support groups, as people feel relaxed and comfortable enough to have a laugh and feel at ease. Humour builds warmth in a group and helps couples cope with some of the difficult and confronting issues that may be part of living with MS.

*"Through meeting together we've learned we're not alone, that other couples have lots of challenges/experiences similar to ours."*

The partners particularly have benefited from having time with each other and openly and safely discussing their experiences of living with MS.

*"The couple's weekends and other meetings with partners have been nothing short of fantastic. Without this opportunity, when faced with sinking or swimming, I would have taken the "sink" option." <sup>(P)</sup>*

*"We realise that everyone has the same issues and together we can work these out." <sup>(P)</sup>*

# Strategies for coping



The couples shared the coping strategies that they each use in their own lives and hope they will be helpful to other couples.

## Maintaining Relationships

*"It is SOOOOO important to have a little time together, when it can be managed. This is also talking!!!! Honest chat to keep up with things, it's too easy to just cruise along and let things slide."*

*"It's important for my partner to have a little time/interest away from home – to stay sane. So I need to foster that and set in place a support option if he's away and things go 'pear shaped'!!"*

*"Be happy about the small things and don't get tied up on times and regularity. You always need to be flexible, learn to deal with disappointment, learn how to deal with your friends and be comfortable being transparent with your communications." (P)*

*"Communication, communication, communication – with lots of laughter!"*

*"Realise and remember that love has a deeper meaning. For me, without a stable relationship it would be difficult to maintain hope."*

*"Love for each other, changed priorities, desire to make the most of what we have and letting go of past expectations. Live day by day, and not year by year. Remember the happy times, and make sure family members (particularly the kids) don't miss out on normality." (P)*

*"Sometimes you need to be tough and say "I am going to have that long awaited beer with my mate", even if home is not in good shape. 'Me time' is very important, but it is always the first thing to be discarded." (P)*

*"Talking about your MS and about how it affects your every day life. Even though people say you look great, it doesn't necessarily mean that you feel great, so letting people know this, especially people close to you."*

*"Teaching my family to focus on what I can do, NOT what I can't."*

*"It's scary for the partner, not knowing what's around the corner. I throw out the long term plans and bring in planning on a daily basis." (P)*

## Managing Constant Change

*"We need to adapt to a different lifestyle. If we can't do it today, try again tomorrow. Things might be different and we may be able to do whatever we want."*

*"I believe you have to keep a positive attitude and take each change a day at a time."*

*"We're proud that we've learnt to accept help from others and that being open about it leads to compassion and understanding from others."*

*"I don't think twice about things anymore, I either do it or I don't. More often I will do it just in case I can't tomorrow."*

## Rebuilding and Maintaining Sense of Self

*"Occasional time out for both of us."*

*"Trying to get out of the MS rut, making time for yourself. This is probably the hardest thing to deal with because you think you are always needed." <sup>(P)</sup>*

*"Having friends who understand. Motivating myself has been vital for example getting out of bed for my children, fixing my hair, getting dressed, doing my makeup (lots of it!!) are all important for my sense of self. Then also doing one little thing for me during the day e.g. exercise, read a few pages, have coffee with a friend, have a nanna nap, do some craft."*

*"Being needed and loved by my partner and children." <sup>(P)</sup>*

*"Having a partner who shows me understanding has made my state of mind bearable."*

*"Being involved in finding the cause of MS would be great. Helping others would certainly be a big step in getting my Self back!"*

*"Learning to love myself, not in a vain egotistical way, but a deep and meaningful way. Forgiving me my failings and appreciating the person I've become."*

*"Believing in myself and staying true to myself."*

*"A work in progress! It needs to happen but may take some time." <sup>(P)</sup>*

## Dealing with Fatigue in Family Life”

*Take turns doing things, do when you can, sometimes make an extra effort, and expect less.” (P)*

*“Make time regularly each day for MS rest, on weekends this may need the other family members to leave the house to enable good quality rest time. This can be frustrating some days, but generally trips out of the house can incorporate visits, shopping or just play time.” (P)*

*“Being flexible with plans allows for better fatigue management. We plan ahead for trips, stopping regularly, do some household tasks on the weekend, divide up jobs, have a comfortable environment for rest.” (P)*

*“I need to be clear when I’m tired and if I’m tired, and let people know – and also take frequent breaks and rest.”*

## Moving Towards New Possibilities in Life

*“Getting involved with the children’s school and helping out a little. I feel safe doing this and it’s manageable and makes me feel productive.”*

*“Going to university and getting good results regardless of cognitive issues – I feel smart again.”*

*“Getting involved with advisory committees, so I have a voice for others with disabilities and I feel as though I may make a difference.”*

*“An inability to say die and to believe that tomorrow is a new day.”*

*“I try to have a positive attitude to get through difficult times.”*

*“Time, prayer, acceptance, focus on positives, see and understand that we have it much better than many others in the world.” (P)*

*“We learn to do more together within the limitations that MS has imposed on us.”*

## Further Reading

There are many excellent books and publications that may be useful to couples throughout their lives. The following are a few that have been identified by couples as being clear and helpful.

Biddulph, S & Biddulph, S (1988)  
The Making of Love, Doubleday, Sydney

Chapman, G (1992)  
The Five Love Languages,  
Strand Publishing, Sydney.

Kalb, R (2006) Multiple Sclerosis  
A Guide for Families, Demos Medical, NY.

King, R (1997) Good Loving Great Sex,  
Random House, Sydney.

Kralik, D, van Loon, A, Telford, K (2005)  
Transition in Chronic Illness Booklet Series,  
RDNS Research Unit, South Australia.

MS in Focus (2003) Special focus on dealing  
with fatigue, Multiple Sclerosis International  
Federation (MSIF) , Cambridge.

MS Essentials 12, (2007) Sex, Intimacy and  
Relationships, Multiple Sclerosis Society, UK

Shadday, A (2007) MS and Your Feelings,  
Hunter House, Ca.

# Final Word

**When asked if anything had changed as a result of attending the Couples' Weekends Away, some responses were:**

*"I have a better understanding of my partner's thoughts and feelings and we have better communication between us...I rediscovered why I fell in love in the first place."*

*"We communicate a lot better than six months ago and I have learned to understand my partner's needs and not just think about myself. We seem more at ease with each other, and I don't take everything on board myself anymore."*

*"The weekends provided me with ideas to reduce the fear factor and reassure me that I was not alone as a carer. I've mellowed—yes—for the good."*

**To other couples who may be considering taking part in a similar couples' program:**

*"If you get the opportunity to take part in a couples' program, JUST DO IT! It was the best thing that myself and my partner have ever done. It saved our marriage."*

We sincerely hope this booklet has been of support to other couples like us:

Angela and Cameron  
Denis and Edi  
Elizabeth and William  
Gemma and Phil  
Lynda and David  
Lynne and David  
Séan and Jill  
Toli and Bronwyn

# Information for Health Professionals

In 2008, the Couples' Project: *Live Fully, Laugh Often, Love Always* was established in southern Tasmania, with enormous and demonstrated success. This was made possible by the generous support of both the Ian Potter Foundation and the MS Society of Tasmania.

The project was developed in response to an identified gap in the provision of meaningful support for couples and families who experience the complexities of MS together.

The Couples' Project was designed to take couples on a journey of building skills and enhancing relationships by learning to LIVE well with MS and better understand each other's needs, learning to LAUGH more as they found other ways and strategies to deal with the feelings and emotions of MS and learning ways of renewing the LOVE through strategies for better communication,

learning to speak each other's love language and exploring sensuality, intimacy and MS. This included two weekends away at a resort on the east coast of Tasmania, follow up focus groups and evening support groups at a local café for people living with MS, and their equally important partners.

We hoped and expected the Project to be a success but have been overwhelmed by the ongoing supportive bond within the group that has gathered strength and developed its own momentum. The original couples are now mentoring new couples and their families, providing living proof that there is a way to continue, enhance and sustain a relationship and family life while living with the uncertainty and challenges of multiple sclerosis.

**For further information about the Couples' Project or services provided by the MS Society of Tasmania, please contact us.**



**A U S T R A L I A**

**Giving life back**

**Head Office**

15 Princes Street  
Sandy Bay TAS 7005  
Tel: 03 6220 1111

**Northern Regional Office**

18/2 Innocent Street  
Kings Meadows TAS 7250  
Tel: 03 6343 1240

**Freecall**

South: 1800 676 721  
North: 1800 654 872

**[www.msaustralia.org.au/tas](http://www.msaustralia.org.au/tas)**