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Information Sheet 52

Practical survival tips for parents of children with additional needs

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There are times when all we want to do is just curl up with a block of chocolate, a magazine or a good movie and shut the door on the world. In our own space we often cry or scream away from everyone and everything.

Parents of children with additional needs feel this more often than most.

This is a list of things to help make life just a little easier. A lot of parents with children with additional needs have contributed to this list and my thanks to each and everyone who will hopefully help someone else with their wisdom.

Naturally not every idea will work for you or fit your family life situation. However it is hoped that some might prove helpful and make you and your family's life a little happier.

You

- The first and most important suggestion is to endeavour to carve out an identity for yourself and fulfil what you believe to be your life's purpose as this is the greatest source of inner happiness and peace. Have something to live for. Know why. Strive to find meaning in your life. Resist the temptation to put yourself last or put your life on hold while you are parenting a child with additional needs. Work hard not to succumb to guilt. Re-prioritise yourself and your life, your hopes and dreams. Design a life plan and set goals. Make it happen. Affirm yourself. If you want to pursue a career or work or volunteer your time, do so.
- Schedule 'me' time, time out and time for fun. Read trashy books, cook, knit, sew, eat chocolate. Organise escapes. Plan things to look forward to. Take turns with your partner in having time out. Learn to do nothing. Take up meditation.
- Pound the street – have regular exercise – go for a walk, join a gym, buy an exercise bike or walking machine for home, play a sport.
- The Healing Power of Touch – indulge and spoil yourself – rub moisturising creams into your body, have foot and body massages, pedicures, facials.
- The Magic of Sleep – get enough rest whenever you can. Take turns to attend to children at night. Do relaxation exercises – Carers Support gives away free tapes. Yoga and aromatherapy can also be helpful. Sleep during the day when the children are at school or ask family members to mind the children during the day so you can sleep if you are especially tired. If you have difficulty sleeping, see your general practitioner.
- Re-energise through recreation. Do things you like. Play (games with the children can be good fun).
- Involve yourself in something that you can totally lose yourself in for a few hours, a day or a week.
- Laugh a lot – especially at yourself. Accept yourself. Watch funny movies and cartoons.

EMBRACING THE DREAMS OF FAMILIES FOR THEIR CHILDREN

Learning Links is a non-profit charity assisting children who have difficulty learning and their families.

We raise funds to help children from birth to 18 years by offering a range of services including the following.

Early Childhood Services for children from birth to six years.

- Early childhood intervention and support for very young children.
- An inclusive preschool for children with and without additional needs.
- An assessment and consultancy service for families who are concerned about their young child's development.
- Specialist early childhood services and therapy.

School Age Services for children from Kindergarten to Year 12 who have low support needs.

- Comprehensive assessments.
- Small group literacy and numeracy support.
- Occupational and speech therapy.
- Outreach programs.
- The Ronald McDonald Learning Program for seriously ill children and Reading and Counting for Life Programs for children falling behind in reading and numeracy.

Family Services helping and supporting families and health professionals.

- Centre and home-based family counselling.
- Parenting Programs and group programs.
- Case Management Services.

Professional Development for teachers and health professionals.

Presentations, workshops and advice on identifying and helping children with learning difficulties, learning disabilities and developmental delays.

Learning Links has branches in six Sydney locations at Peakhurst, Penshurst, Fairfield, Miller, Brookvale & Randwick. We also offer services to children in country NSW, the ACT, other Australian states and New Zealand. A complete list of branch locations and contact numbers is on the back cover.

Learning Links

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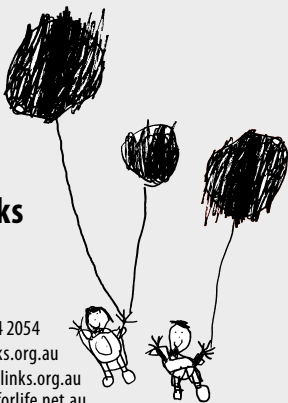
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You and your partner

- Foster your relationship with your partner – this can be an easy oversight. Communicate your needs and thoughts to one another; even if this is just for 10 minutes before bed. Often with so much happening, it is easy to focus on what needs to be done and although you might be working together to achieve this, it is also easy to overlook each other's individual needs.
- Spend time just 'schmoozing' with your partner. It will glue your relationship together. Watch videos at home, have breakfasts, lunch or dinner out. Try to taste the food. Go to the movies or out dancing. Enjoy the moment – try not to talk about finances or the children.
- Establish a workable relationship with your spouse. Agree or compromise on interventions to avoid having to take on each other as well as the various systems (medical, community services or educational) in your life.

Your home

- Work to create a home that brings you happiness to live in – environment is all important.

Your children

- Spend time with all the children in the family. Try not to allow the child with additional needs to permanently dominate family life so that family life doesn't revolve around that child or the needs of that child doesn't restrict sibling participation in life. There will be all consuming ups and downs and highs and lows as new issues emerge, but aim to meet the needs and interests of all children in the family as much as possible, most of the time.
- Don't get housebound. Go out and take the family with you. If respite is not an option for your family but it is difficult for you to take the children out together by yourself, find a family member, friend or volunteer (for example; through a church group) so everyone in the family can enjoy the outing and your time can be shared between your children.

Social participation

- Find someone you can talk to authentically without judgement or blame, put downs or insults. Maintaining good friendships will decrease any feelings of social isolation you might experience.
- Do something for someone or a service, volunteer, give a talk, feel you are contributing to your community. Help someone who is new to the disability field. Make someone's day. (Support groups can be very helpful to achieve this.)

Your emotional health

- Think daily about the positives in your life or things that you are grateful for. Words fuel emotion. Happiness is determined more by our minds than our circumstances.
- Express your feelings. All of them. Even sadness. Words in themselves are nothing – they are simply tools to communicate the deepest messages of our soul. It does not mean that you are not coping or require drugs. Open communication happens when we actively listen to each other and try to understand each other's world. Effective communication happens when it is in a form that can be heard. Try and put 20 seconds between felt emotions and expressions of hurt and rage.
- Talk to your doctor if you think you need counselling, medication or psychological treatment (for example, cognitive behavioural therapy) to manage your moods.
- Keep a journal, write your thoughts down, write poetry, compose lyrics or play music.

Rewire your brain

- Control your thoughts – work hard to change unhelpful ways of thinking – especially the automatic negative thoughts like 'Why me?' 'Why us?' questions or psychological traps such as 'There is nothing I can do to change the situation' or 'It's all too hard'. When you start worrying, go back to the *now*, try not to focus on your problem and distract yourself. Remember thoughts are thoughts, they are not facts.
- Develop an awareness of what is changeable in life and what is not.



- Train your mind to be more positive during the night. Write down two things that have worked out each day or some little progress your child has made in a diary before you go to bed.
- Redefine the situation – especially what it means in the larger context of your life's purpose.
- Remember how and what got you through previous difficulties. Key into your own inner strength.

To cope

- Go on the web, find information and educate yourself about the disability and associated services. Learn the jargon. Join a chat room or support group and share with others.
- Accept that you cannot do it all by yourself. Decide what supports you need and feel confident to ask for them. Persist. Make use of the supports around you. Get anything that is available; use everything that is offered.
- Take a risk with respite and any other helpful service that's out there that can give you a bit of assistance or a break. Don't be put off by waiting lists. Avoid the trap of 'no one can look after my child like me'.

- Try not to become caught up into the trap of being both therapist and parent. Build 'therapies' into normal routine tasks of daily living.
- Slow down, simplify, and cull any service, therapy or therapist that is not working for your family.
- Build rapport with your service providers – strive to be a cooperative team. Use waiting times wisely.
- Identify and work at decreasing the outside pressures and demands that cause you angst and guilt. Set your boundaries and try not to overload your days. Have a long hard look at your own expectations of what you think you should be doing.

Organisation

- Keep a book at home that contains lists of things to be done.
- Have one communication book to go between all therapies and educational systems.
- Establish a file on your child and keep everything in the one place. Write your own progress reports six monthly and yearly.

- Organise family life with a whiteboard. Having a loose, flexible timetable for set daily activities can be helpful.

And to survive ...

- Anticipate stressful times and prepare for them.
- Love generously. If you want to be happy, you need to feel loved. To receive love, you have to give out love and respect.
- Slow down and switch off all the noise around you.
- Keep putting one foot in front of another ...

Further reading: Dr Timothy Sharp, The Happiness Handbook, Finch Press, Sydney.



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– all enquiries to Head Office

School Age Services
– contact your local branch

Family Services
– contact your local branch

All other enquiries
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