

## Summary Sheet

### 1. Help and Support

# Top Twenty Strategies for Managing Life<sup>1</sup>

1. **Celebrate your Child:** Before worrying, or thinking about any other issues or attaching labels remember the miracle of a child's very existence.
2. **Choose to focus on what's going right:** Try to celebrate the successes (no matter how small) rather than dwell on those less than positive aspects.
3. **Get beyond the "why" to the "how":** Accept your child as they are, stop waiting for the "miracle cure". (This isn't to say you shouldn't keep up to date with new developments.)
4. **Appreciate what your child contributes to others:** Remember that your child is part of interactions and part of the lives of a number of people who will rely on them for a whole range of benefits; it is not all a one-way street.
5. **Trust your instincts:** If from your experience things don't seem right, they probably aren't.
6. **Don't go it alone; ask for help:** One of the most widely reported ways of coping with the challenges of raising a child with a disability, is seeking and receiving appropriate help and assistance.
7. **Reassess success:** Throw out old definitions of "success"; your child's circumstances require different criteria.
8. **Utilize planned perseverance:** Recognise and accept that you are going to need to deal with the same issues time and again, in a range of settings, with a range of people.
9. **Be a parent first:** Before you realized your child has a disability, you were a parent, (as you may be for others,) you will feel better if you keep this in mind, before dealing with any "disability issues".
10. **Keep your sense of humour:** Remember that saying about "Laughter being the best medicine".
11. **Be flexible day to day:** Some parent's have found "colour coding" the day to be a help; *White Days* (the good days), *Grey Days* (the not so good ones) and *Black Days* (the really bad ones), and plan the day accordingly.
12. **Give yourself "Time out":** Respite is widely reported and recognised as a way of coping with the additional burdens of raising a child with a disability.

---

<sup>1</sup> Adapted from Scorgie, K., & Wilgosh, L., (2002) Journeys Through the Land of Oz: Parents' top Twenty Strategies for Managing Life. *The Exceptional Parent*, Nov., (32) 11. 30-32.

**13. Allow yourself “ups” and “downs”:** Just like other aspects of life, it has its good and not so good aspects.

**14. Remember to nurture your marriage:** Before you were the parents of a child with a disability, you were a couple, you need to nurture and care for this primary relationship.

**15. Be a family:** In your role as parent, you need to expect and plan to be, a guiding influence on how the family does things as a family.

**16. Balance time together with each of your children:** While recognising that the child with a disability has additional needs, these need to be balanced with the needs of other children, for the undivided attention (on occasion) of their parents.

**17. Know what you want and go for it:** Don't necessarily take a “no” as final. If you do your homework, and put up a good case, you may get more than you expected. (Sometimes saying “no” is just the easy way out.)

**18. Be resourceful: find ways to be understood:** Try to identify what the actual “problem” is, to try to find a solution. E.g. it may be appropriate to videotape a particular behaviour, or situation, to show others exactly what happens.

**19. Connect with other parents:** There's nothing like being able to speak with someone who's “Been there-Done that!” whether it is face to face (as part of a formal or informal group, or meeting), by phone, email, internet chat room, or whatever.

**20. Value the journey:** Be aware that like the journey of life, with its twists and turns, the raising of a child with a disability is a journey, and you will learn things along the way that you may not have otherwise.

# 1. Help and Support: Top 20 Strategies for Managing Life

There's no two ways about it, research<sup>2</sup> and experience from raising a child with a disability<sup>3</sup>, show it is even more difficult than raising a child without a disability. Research to show that:

In spite of the unique demands of parenting a child with a disability, many parents have reported that they have not only been able to manage their lives effectively, but they have also experienced beneficial outcomes related to parenting their children.<sup>4</sup>

The article "*Journeys Through the land of Oz: Parent's Top Twenty Strategies for Managing Life*" by Kate Scorgie, and Lorraine Wilgosh<sup>5</sup>, provide the headings as starting points for this detailed information sheet.

## 1. Celebrate your Child: Before worrying or thinking about any other issues or attaching labels, remember the miracle of a child's very existence.

Dr Robert Naseef an American psychologist who specializes in working with families of children with special needs, writes in his book *Special Children Challenged Parents*<sup>6</sup> about the birth of his son, and although he later discovers his son has Autism, his feelings at the time of the child's birth are no doubt like that of many parents:

I'll never forget the night that you were born. It was more than incredible; indeed it was magical. [He goes on to say.] Without thinking about it, I jumped from my position behind the delivery table and wound up right there beside the doctor—my knees wobbling and my heart pounding with excitement. ....

Ever since then I have held a special respect for a woman's ability to give birth—for every woman's special partnership in the miracle of life. I thought of my mother who gave birth to eight healthy children. That was a new beginning in my consciousness. Through you [his son Tariq] the wonder of life began to be revealed to me in a way that I could never have imagined. Now I know firsthand what author Kahlil Gibran means about how inextricably woven together are our moments of joy and sorrow. (p. xvii – xviii)

---

<sup>2</sup> e.g. Rogers, M., & Hogan, D., (2003) *Family Life With Children With Disabilities: The Key Role of Rehabilitation*. Journal of Marriage and the Family. 65 (4) 818-833, Keller, D., & Honig, A., (2004) *Maternal and Paternal Stress in Families with School-Aged Children with Disabilities*. American Journal of Orthopsychiatry 74 (3) pp. 337-348.

<sup>3</sup> e.g. deRocher Lermer, T, (2004) *CDIP Update: Life in the Trenches: A Provider's View of Raising a Child with Disabilities* Division 22 Newsletter Division 22 Newsletter Winter 2004 Volume 31, No. 2.

<sup>4</sup> Page 1., Wilgosh, L., Nota, L., Scorgie, K., & Soresi, S. (2004) *Effective Life Management in Parents of Children with Disabilities: A Cross-National Extension* *International Journal for the Advancement of Counselling, Vol. 26, No. 3, September 2004*

<sup>5</sup> Scorgie, K., & Wilgosh, L., (2002) *Journeys Through the Land of Oz: Parents' top Twenty Strategies for Managing Life*. The Exceptional Parent, Nov., (32) 11., 30-32.

<sup>6</sup> Naseef, R., (2001) *Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a disability*, (Revised Edition.) Baltimore, Maryland: Paul H. Brookes Publishing Co.

## 2. Choose to focus on what's going right:

Try to celebrate the successes (no matter how small) rather than dwell on those less than positive aspects. Remember that line from an old Harold Arlen song:

*“Ac-cent-tchu-ate the positive E-lim-i-nate the negative, And latch on to the affirmative, Don't mess with mister inbetween”*

## 3. Get beyond the “why” to the “how”: Accept your child as they are, stop waiting for the “miracle cure”.

This isn't to say you shouldn't keep up to date with new developments. But the sooner you accept that this is what the situation is, the sooner you can move forward.

Research<sup>7</sup>, and the accounts of people who have children with a disability, like that of Robert Naseef, (referred to earlier) often refer to the *transformation* of the person as a result of having a child with a disability. While the initial news may come as a shock, and the disintegration of life as you knew it, this has been described as a “positive disintegration” as it provides:

...an opportunity, an open doorway toward growth; it is, in fact, necessary or there will be no growth, just stagnation. Disintegration is not something we grow in spite of; it is something we grow because of. It is a profound fact of the human condition.<sup>8</sup>

One parent, who also worked in service provision for 27 years, notes how:

Parents are acutely aware of the competing environmental, genetic, disease process and many others, generally unproven, explanations for disabilities. And no one has questioned more pointedly and deeply what role we played in our Children's disabilities than have we. Those questions are never truly resolved for most of us. We simply make the best peace we can with them and move on to tackle the more immediate and pressing task of finding the energy and resources to meet our Children's needs now. As a result, we tend to become defensive if a provider – or anyone else - hints at resurrecting the question of “Did I cause this”?<sup>9</sup>

It may be a case of trying to get to the level of acceptance where like the (U.S.) Resource Foundation for Children with Challenges<sup>10</sup> say on their T-shirt “We all draw our Rainbows with the Colors we are Given”.

---

<sup>7</sup> Scorgie, K., & Sobsey, D., (2000) Transformational Outcomes Associated With Parenting Children Who Have Disabilities. *Mental Retardation*, Volume 38, Number 3, pp 195 – 206, give a number of examples of this, in both technical literature and various biographies.

<sup>8</sup> . Hague 1995, cited in Scorgie & Sobsie (2000).

<sup>9</sup> deRocher Lerma, (2004) CDIP Update: Life in the Trenches: A Provider's View of Raising a Child with Disabilities [APA] Division 22 Newsletter Winter 2004 Volume 31, No. 2, p. 8-11.

<sup>10</sup> See <http://www.specialchild.com/marketplace.html> for more details.

#### **4. Appreciate what your child contributes to others:**

Remember that your child is part of interactions and part of the lives of a number of people, who will rely on them for a whole range of benefits; it is not all a one-way street.

For example, some note how having a child with a disability allows a mother to stay home with her child, where other's do not have that choice<sup>11</sup>.

#### **5. Trust your instincts: If from your experience things don't seem right, they probably aren't.**

Apart from anything else, research supports the idea of taking account of parent's instincts.<sup>12</sup> Research shows this is one of the strategies of those who cope well with the parenting a child with a disability.<sup>13</sup>

#### **6. Don't go it alone; ask for help: One of the most widely reported ways of coping with the challenges of raising a child with a disability is seeking and receiving appropriate help and assistance.**

Time and again, the research shows that seeking out and receiving help are some of the best ways of coping with the extra burdens of having a child with a disability.

West Australian research<sup>14</sup> shows that parent's of a child with a disability often find the LAC (Local Area Co-ordinator) was able to assist with practical things like funding and equipment.

One researcher writes of a member of a support group saying how:

I guess it [the support group] keeps us sane, knowing that ... we're not alone here and you're not the only one it's happened to.

You do, you know, you have a bit of a laugh about it at least.  
And a bit of a cry.

Yes the freedom to feel that you can talk to a group of people who actually want to hear what you've got to say.

And they don't think you're neurotic and off your tree!<sup>15</sup>

---

<sup>11</sup> Rogers, M., & Hogan, D., (2003) Family Life With Children With Disabilities: The Key Role of Rehabilitation. Journal of Marriage and the Family. 65 (4) 818-833.

<sup>12</sup> Webb, C.L. (2005) Parents' perspectives on coping with Duchenne muscular dystrophy. Child: Care, Health & Development. Vol. 31 (4) 385 – 396.

<sup>13</sup> Wilgosh, L., Scorgie, K., & Fleming, D., (2000) Effective Life Management in Parents of Children with Disabilities: A Survey Replication and Extension Developmental Disabilities Bulletin. Vol. 28, Iss. 2; p. 1-14 refer to 3 of their own previous studies to support this.

<sup>14</sup> Monterosso, L., Kristjanson, L., Phillips, M., Rowell, S., & Watson, M., (2005?) Paediatric Palliative and Supportive Care – Caring for Life: The needs of children and families in Western Australia. Churchlands, Western Australia: Edith Cowan University, School of Nursing, Midwifery and Postgraduate Medicine.

<sup>15</sup> van Kraayenoord, C., (2002) "I once thought I was a lousy mother": the role of support groups. International Journal of Disability, Development and Education, Volume 49, Number 1 / March 01, p. 4-9

The same researcher notes how being told face to face, that “You are not a lousy mother” by someone who knows what it is like, can have a profound, and positive effect.

From their website<sup>16</sup>, Carers Australia provide the following advice about “*Taking care of yourself – a checklist*”

- Do I have someone I trust to talk to about how I’m feeling?
- Am I trying to get some regular exercise?
- Am I trying to get enough rest and sleep?
- Am I trying to eat regular meals?
- Do I get enough breaks from caring?
- Have I got some regular times for relaxation?

**7. Reassess success: Throw out old definitions of “success”; your child’s circumstances require different criteria.**

As Terry DeRocher Lerma says;

Our “wins” are often what others in other circumstances might define as losses, but we need to celebrate them and would prefer to share them with others who can truly appreciate that they are “wins” for us and our Children.

She later goes on to say;

As Parents, we *do* have a rather large peer group within which to share our “wins”. And we clearly need to be able to celebrate our own and our Children’s successes, and share our challenges, with our own and/or our Children’s service providers. If we cannot do so, we and our Children cannot fully benefit from what providers offer, and our many challenges make it imperative that we make the best use of every resource available.<sup>17</sup>

---

<sup>16</sup> “Information for Carers – Looking after yourself” [Retrieved from <http://www.carerswa.asn.au/uploadedfiles/Taking%20Care%20of%20Yourself.pdf> 15<sup>th</sup> May 2006]

<sup>17</sup> DeRocher Lermer, T, (2004) *CDIP Update: Life in the Trenches: A Provider’s View of Raising a Child with Disabilities* [American Psychological Association] Division 22 Newsletter Division 22 Newsletter Winter 2004 Volume 31, No. 2.

**8. Utilize planned perseverance: Recognise and accept that you are going to need to deal with the same issues time and again, in a range of settings, with a range of people. “Get used to it!”**

Three pieces of advice from the mother of a child with multiple disabilities were:

1. “Even if you are smart or semi-smart, you get overwhelmed.”
2. “Hang in there till you find the right doctor.”
3. “Never give up!”<sup>18</sup>

One of the issues you are going to need to deal with time and again is the responses of others to your child with a disability. Appendix B is a summary of ideas and strategies, as described in “Facing the Crowd” by Deborah Fullwood and Peter Cronin<sup>19</sup>, for dealing with this issue.

Although written in the context of treatment for an uncommon blood cancer, the observations by Stephen Schneider can be applied to having a child with a disability and the same sort of medical bureaucracy;

Confronting the rules, regulations, and hierarchical structures inherent in most hospitals is intimidating enough for any ordinary person, let alone one numbed by a terrible diagnosis. Thus, most physicians—and patients—act as if the patients [or in this case parents] role is simply to take orders and be cooperative. Tradition suggests that only medical experts should decide on what treatment to take; patients are presumed both incapable of material contribution to such decisions and likely to have a poorer prognosis if they are even made aware of the dark side of treatment.

But sometimes the patient [or parent] knows better, at least about how the patient feels and what the patient needs. By facing the hospital bureaucracy and convincing doctors to individualize diagnostic tests and re-examine some conventional practices, a patient [or parent] may be able to improve his or her chances of survival [or the child’s quality of life]...I am convinced that my persistence and my insistence on partnering with my doctors in redesigning several aspects of my medical treatment, rather than just picking from a short menu of standard protocols has contributed to my continuing survival. The feistiness you may observe in me as my story unfolds not only helped me form a partnership with my doctors, it also allowed me to emerge from my cancer experiences with high energy and a fighting spirit.<sup>20</sup>

Research supports the idea of parents, and the medical and other support staff working as a team. One provider (who is also a parent of a child with disabilities) says how she would much rather work as a “...partner, contributing to the well-being

---

<sup>18</sup> Marsha Longdon, quoted at p.144 of Thompson, C., (2000) Raising a handicapped child: a helpful guide for parents of the physically disabled. New York : Oxford University Press.

<sup>19</sup> Fullwood, D., & Cronin, P., (1986) Facing The Crowd: Managing other people’s insensitivities to your disabled child. Melbourne, Victoria: Royal Victorian Institute for the Blind.

<sup>20</sup> P. xiv-xv of Schneider, S., (2005) The Patient From Hell: How I worked with my doctors to get the best of modern medicine, and how you can too. Cambridge: MA: De Capo Press.

of Parents and their Children, to that of a benevolent, omniscient expert, destined to disappoint those for whom I assume responsibility.”<sup>21</sup>

**9. Be a parent first: Before you realized your child has a disability, you were a parent, (as you may be for others) you will feel better if you keep this in mind, before dealing with any “disability issues”.**

Parents will, depending on a number of factors, have different expectations about their partner and the roles and expectations of the parenting role.

In working with couples groups, of parents of children with a disability, Robert Naseef looked at what their partners wanted. Some of the things wanted were related to the special challenges involved with these children, some were more generic.

What the participants in his research and groups said is detailed in this table<sup>22</sup> which continues onto the next page.

| What Men thought women wanted  | What the men wanted from the women in their lives  |
|--|--|
| <ol style="list-style-type: none"> <li>1. Women have it harder because they need more practical help in the everyday things. It's just too much to handle. A nanny would be ideal, but a teenager to help out for a few hours a day with child care or household chores would be great.</li> <li>2. Women need more understanding and compassion from their husbands. We need to communicate more and listen to how they feel.</li> <li>3. Women want to talk about other things, too—not just the child with the disability.</li> <li>4. Women need more physical help when the man is home; they're worn out from the everyday grind.</li> <li>5. Women want men to play with the child with special needs more and get to know more about him or her.</li> <li>6. Women want men to take the children out and give the woman some free time for herself.</li> <li>7. Women want men to assume more responsibility around the house.</li> <li>8. Women want men to pay more attention to how the woman is feeling and what she might need or want each day.</li> </ol> | <ol style="list-style-type: none"> <li>1. We want the women to understand that we are trying to help in the way we know how and that we're frustrated when we can't make things better.</li> <li>2. We need more time as a couple again, to be together without the children.</li> <li>3. We want women to be more rational and less emotional so that we can discuss problems and find solutions.</li> <li>4. Let us as men take more responsibility with the child with special needs. Sometimes it seems that the women can't let go of doing all of the work and being overwhelmed all of the time. Let's get more organized and distribute the work.</li> <li>5. We need more strength and stability in our marriage. It would help if they told us what we are doing right so that we could feel more secure in the relationship.</li> </ol> |

<sup>21</sup> P.11, DeRocher Lerma, (2004) CDIP Update: Life in the Trenches: A Provider's View of Raising a Child with Disabilities. [American Psychological Association] Division 22 Newsletter Winter 2004 Volume 31, No. 2, p. 8-11.

<sup>22</sup> Adapted from p.161-164, Naseef, Robert, (2001) Special children, challenged parents: the struggles and rewards of raising a child with a disability (Revised Edition.) Baltimore: Ill., Paul H Brookes Publishing Company.

| <p style="text-align: center;"><b>Why the women thought it is hard to be a man</b></p>  | <p style="text-align: center;"><b>What the women wanted</b></p>   |
|---|---|
| <ol style="list-style-type: none"> <li>1. Men have an extremely hard time with all of the intense emotions involved with the child with special needs. They want women to be more rational and more supportive of their style of caring.</li> <li>2. Men feel unappreciated for their efforts especially for how hard they work to pay the increased medical bills and so forth.</li> <li>3. Women are so intense that men feel like they're getting nagged all of the time.</li> </ol> | <ol style="list-style-type: none"> <li>1. The men to be involved in the child's education; they were tired of going to the meetings alone; they wanted the men to try whenever possible to take a few hours off from work to be with them at these times.</li> <li>2. Some time alone to relax without the children.</li> <li>3. To be able to talk about their feelings without the men getting defensive.</li> <li>4. Time together as a couple.</li> <li>5. Men to develop a better understanding of their child's special needs and not leave it all to the women.</li> </ol> |

### **10. Keep your sense of humour:**

Remember that saying about "Laughter being the best medicine". As Robert Naseef notes in *Special Children: Challenged Parents*, in doing his doctoral research on families that coped successfully with disability "*Each and every family told me that a sense of humour had helped them survive and even prevail through the problems they faced.*" (p. 218)

Research into how humour can help families cope with a disability notes that the use of humour helps;

- a) To lessen tension and stress;
- b) To assure safety and freedom;
- c) To reduce pain;
- d) To express emotion;
- e) To initiate an acceptance;
- f) To diminish the tragedy and empower;
- g) To cope with disability.<sup>23</sup>

<sup>23</sup> Rieger, A., (2004) "Make it Just as Normal as Possible with Humor" Mental Retardation, 42 (6) 427-444.

### **11. Be flexible day to day:**

Some parents have found “colour coding” the day to be a help, *White Days* (the good days), *Grey Days* (the not so good ones) and *Black Days* (the really bad ones), and plan the day accordingly.

### **12. Give yourself “Time out”:**

Respite is widely reported and recognised as a way of coping with the additional burdens of raising a child with a disability.

This may mean arranging a scheduled time, on a regular basis for time when you are not responsible for your child. E.g. a weekly evening for yourselves, or arranging a weekend a month, or every six weeks, for yourself and your partner, whether this involves paid or volunteer (e.g. other family members and friends) “Babysitters” will depend on your individual circumstances.

### **13. Allow yourself “ups” and “downs”:**

Just like other aspects of life, raising a child with a disability has its good and not so good aspects.

### **14. Remember to nurture your marriage:**

Before you were the parents of a child with a disability, you were a couple, you need to nurture and care for this primary relationship.

Research on the effects on a marriage of having a child with a disability (and the likelihood of divorce) appears to be inconsistent.<sup>24</sup> However, it may also be worth taking into consideration the following part of Robert Naseef’s book “*Special Children: Challenged parents*”.

#### *Imperfect Relationships*

Just as parenting even a typical child requires giving up the dream of the perfect child, a rewarding and enduring marriage calls on us to abandon our longing for the perfect union in which all of our needs are met and our partner is also totally satisfied. Relationships can be incredibly complex and seldom are quite what we expect. My own daily experiences remind me of my trials and frailties, and as Helen Featherstone observed in *A Difference in the Family: Life with a Disabled Child*, insight cannot solve every problem that comes up. It is, however, an important tool to maintain the love between a couple when the very fabric and meaning of life is challenged by disability in the family. For some people, a child’s disability may reveal problems in a marriage that no amount of understanding and insight can repair or pave over, and divorce may ensue. For others, a child’s special needs can be a

---

<sup>24</sup> See, e.g. page 196, of Scorgie, K, & Sobsey, D., (2000) *Transformational Outcomes Associated with Parenting Children Who Have Disabilities*, *Mental Retardation*, Volume 38, Number 3, pp 195 – 20.

red herring that distracts a couple from fundamental issues about their relationship. Problematic relationships can become considerably worse. Because 47% of first marriages fail, around 57% of all marriages end in divorce, according to the U.S. Census Bureau, none of us can afford to be smug.

Hope for relationships can, however, spring from the crises that couples experience when their child has a disability. “Normal” crises such as childbirth, moving, loss of a job, financial problems, and trials in parenting can all strain a relationship in parallel ways. Many have observed that ordinary trouble differs only in degree from the strain caused by disability. In my view, however, having a child with a disability is a quantum leap away from everyday problems, but it is nevertheless an experience that prepares us to learn from life.<sup>25</sup>

Appendix C provides further information on ‘What Makes a Healthy Relationship?’

### **15. Be a family:**

In your role as parent, you need to expect and plan to be, a guiding influence on how the family does things as a family.

One mother said how she needed to be firm, and assertive, or the “Rudder” of the family, to ensure they kept on-task, rather than get distracted, and using up a lot of time and energy on less important matters.

### **16. Balance time together with each of your children:**

While recognising that the child with a disability has additional needs, these need to be balanced with the needs of other children, for the undivided attention (on occasion) of their parents.

This may mean preparing a timetable that is posted in a prominent place with specific times or activities to be done, for all members of the family, including respite or free time for the parents.

When designing a timetable, it is important to ensure that each of the children has specific, and scheduled time alone with each and both of the parents, and that the parents also have time set aside for themselves, individually and as a couple.

Depending on the age and reading ability of the children, it may be necessary to use pictures to show the activity (if made on a computer, this may mean using clip art, or special characters,) or if hand drawn using stick drawings, or pasting photos or clippings from magazines, newspapers, or junk mail etcetera.

Depending on the computer literacy, or artistic ability of the children, this could be a particular task for one, or more of the children, once the day, time, and activity details are decided.

---

<sup>25</sup> P. 167 Naseef, Robert, (2001) Special children, challenged parents: the struggles and rewards of raising a child with a disability (Revised Edition.) Baltimore: Ill., Paul H Brookes Publishing Company.

Whether it is a small page, or a poster, or somewhere in between, will depend on individual circumstances.











Other factors to consider, include that it has a limited life, and is reviewed (for example) every three months to take into account changing circumstances, like

school holidays, changing exercise routines, changes in mobility and independence, (of the child with a disability and their siblings).


For families with children who have a degenerative condition, the creation and changing of the timetable could be a quarterly family ritual which recognises and acknowledges the changes that may occur and help plan for these.

A “family timetable” could look something like the version on the following page.

## THE SMITH FAMILY DAILY ACTIVITIES - August to October

| MON   | TUE  | WED  | THU  | FRI   | SAT   | SUN  |
|---|--|--|--|---|---|--|
| 7.30 -8am<br>Mum & Dad<br>& one of the<br>children#<br>take Spot<br>for a walk<br><b>M D</b><br><b>K/J/N/G</b><br> | 7.30-8am<br>Gemma &<br>Mum take<br>Spot for a<br>walk<br><b>M G</b><br> | 7.30-8am<br>Kylie &<br>Mum take<br>Spot for a<br>walk<br><b>K M</b><br> | 7.30-8am<br>Nick & Dad<br>take Spot<br>for a walk<br><b>D N</b><br>                     | 7.30-8am<br>Mum & Dad<br>take Spot<br>for a walk<br><b>M D</b><br>  | 8.30-9am<br>Jason &<br>Mum take<br>Spot for a<br>walk.<br><b>M J</b><br> | 8-9.30am<br>Whole<br>family goes<br>to Macca's<br>for<br>Breakfast<br>Then take<br>Spot to park<br><b>M D</b><br><b>K J N G</b><br> |
|   |  | 10.30am<br>Mum's<br>fortnightly<br>Carer's<br>meeting<br><b>M</b>       |  |   | Kylie, Nick,<br>& Gemma<br>go to<br>Siblings<br>group<br>(Fortnightly)<br><b>N K G</b>  | 11am-12<br>Dad &<br>Jason play<br>computer<br>game<br><b>D J</b>   |
| 4-5pm<br>Jason does<br>his Physio<br>exercises  | 4-5pm<br>Jason does<br>his Physio<br>exercises   | 4-5pm<br>Jason does<br>his Physio<br>exercises   | 4-5pm<br>Jason does<br>his Physio<br>exercises   | 4-5pm<br>Jason does<br>his Physio<br>exercises  | 4-5pm<br>Jason does<br>his Physio<br>exercises  | 4-5pm<br>Jason does<br>his Physio<br>exercises   |
|   | 5pm-6pm<br>Gemma<br>helps Mum<br>prepare<br>dinner<br><b>M G</b>   | 5-6pm<br>Kylie helps<br>Mum<br>prepare<br>dinner<br><b>K M</b>   | 5 -6.30pm<br>Gemma<br>helps Dad<br>do the<br>weekly<br>shopping.<br><b>G D</b>   | 6.30pm<br>Mum & one<br>of the<br>children# go<br>to local<br>Pizza Shop<br>& Video<br>store to get<br>pizza &<br>movie<br> | 6.30 – 8pm<br>Mum & Dad<br>Dinner by<br>themselves<br>at local<br>pub*  |  |
| 5pm-6pm<br>Dad helps<br>Gemma<br>with reading<br>or<br>homework<br><b>D G</b>   | 4pm-5pm<br>Mum helps<br>Nick with<br>homework<br><b>M N</b>  | 7-7.30pm<br>Dad &<br>Jason do<br>reading or<br>homework<br><b>D J</b>  | 7 – 10pm<br>Dad's night<br>out with the<br>Mates, or<br>Fathers<br>group<br> <b>D</b> | Dad reads<br>to or with<br>Kylie<br><b>D K</b>  |   | 10am-12<br>Kylie helps<br>Dad do the<br>laundry<br>washing<br><b>D K</b>   |

Family = Mum (**M**) and Dad(**D**), Nick(**N**), Gemma(**G**), Kylie(**K**) Jason(**J**), and

Spot the dog  . (Jason is the child with a disability)

\* = Babysitter/Respite carer arranged.

# 1<sup>st</sup> week of month Kylie, 2<sup>nd</sup> Jason, 3<sup>rd</sup> Gemma, 4<sup>th</sup> Nick.

## **17. Know what you want and go for it:**

Don't necessarily take a "no" as final. If you do your homework, and put up a good case, you may get more than you expected. (Sometimes saying "no" is just the easy way out.)

On many occasions you may need to act as an advocate for your child with a disability. Being an advocate does not mean being rude and obnoxious to service providers to get what you want. Advocacy has been described as:

...a non-violent empowerment and support process, through which families with disabled relatives can constructively express dissatisfaction and contribute creative solutions to problems existing in human service systems.<sup>26</sup>

Parents, who use advocacy, refer to a reduction in stress and an improved quality of life<sup>27</sup>.

Parents who cope well with raising a child with a disability, include those who;

1. Trust their instincts about what is good for the child;
2. Collaborate effectively with professionals;
3. Have the personal traits of patience, determination, and a positive outlook on life.<sup>28</sup>

## **18. Be resourceful: find ways to be understood:**

Try to identify what the actual "problem" is, to try to find a solution. E.g. it may be appropriate to videotape a particular behaviour or situation to show others exactly what happens.

## **19. Connect with other parents:**

There's nothing like being able to speak with someone who's "Been there-Done that!" whether it is face to face (as part of a formal or informal group or meeting), by phone, email, internet chat room, or whatever.

For those parents from a non-English speaking background, it can be difficult to find resources, support and assistance.

*Carer's WA* says on their website<sup>29</sup>:

---

<sup>26</sup> Munro (1991) cited at p. 39, Nachshen, & Jamieson, J., (2000) Advocacy, Stress and Quality of Life in Parents of Children with Developmental Difficulties. Developmental Disabilities Bulletin Vol. 28 (1) pp. 39-55.

<sup>27</sup> As above, page 47.

<sup>28</sup> Wilgosh, L., Scorgie, K., & Fleming, D., (2000) Effective Life Management in Parents of Children with Disabilities: A Survey Replication and Extension Developmental Disabilities Bulletin. Vol. 28, Iss. 2; p. 1-14.

<sup>29</sup> [Retrieved from <http://www.carerswa.asn.au/services/cald.asp> 15th May 2006.]

Carers from Culturally and Linguistically Diverse (CALD) backgrounds often face additional issues such as:

- Cultural differences leading to misinterpretation and misunderstanding
- No knowledge of existing culturally appropriate support services and how to access them
- No access to translated information
- No support from extended family (when only parts of the family are resident in Australia)
- Social isolation leading to the feeling of exhaustion

*Carers WA* also refer on their website ([www.carerswa.asn.au](http://www.carerswa.asn.au)) to some of the supports available to carers from CALD backgrounds.

**20. Value the journey: Be aware that like the journey of life, with its twists and turns, the raising of a child with a disability is a journey, and you will learn things along the way that you may not have otherwise.**

Some American research<sup>30</sup> has summarised positive aspects of raising a child with a disability, as identified by families, these include:

- a. Pleasure/satisfaction in providing care for the child
- b. Child is a source of joy/happiness
- c. Sense of accomplishment in having done one's best for the child
- d. Sharing love with the child
- e. Child provides a challenge or opportunity to learn and develop
- f. Strengthened family and/or marriage
- g. Gives a new or increased sense of purpose in life
- h. Has led to the development of new skills, abilities or new career opportunities
- i. Become a better person (more compassionate, less selfish, more tolerant)
- j. Increased personal strength or confidence
- k. Expanded social and community networks
- l. Increased spirituality
- m. Changed one's perspective on life (e.g. clarified what is important in life, more aware of the future)
- n. Making the most of each day, living life at a slower pace (p. 118)

---

<sup>30</sup> Hastings, R., & Taunt, H., (2002) Positive Perceptions in Families of Children With Developmental Disabilities. American Journal on Mental Retardation 107 (2) p. 116-127.

## **RESOURCES:**

Baker, B., & Brightman A. J., (with Blacher, J. B.,) (2004) Steps to Independence: Teaching Everyday Skills to Children with Special Needs. Baltimore: Ill., Paul H Brookes Publishing Company. [ISBN: 1-55766-697-0]

Cerebral Palsy Association of Western Australia Ltd. (1995) How can I help? : Information for friends and relatives of a child with cerebral palsy. Coolbinia, W.A. ,

Cerebral Palsy Association of Western Australia Ltd. (1996) How do I feel?: Adjusting to my child's disability Coolbinia, W.A. ,

Cerebral Palsy Association of Western Australia. (2000-2002) ; [editor, Joy Tranter]. Country kids first: Coolbinia, W.A.

Exceptional Parent Magazine <http://www.eparent.com/>

Naseef, Robert, (2001) Special children, challenged parents: the struggles and rewards of raising a child with a disability (Revised Edition.) Baltimore: Ill., Paul H Brookes Publishing Company [ISBN: 1-55766-535-4 ]

Salovey, P.; Mayer, J. D.; Caruso, D, (2003) Measuring emotional intelligence as a set of abilities with the Mayer-Salovey-Caruso Emotional Intelligence Test. In S. J. Lopez, & C. R. Snyder, (Eds.), Positive psychological assessment: A handbook of models and measures. (pp. 251-265) Washington, DC: US: American Psychological Association.

Sandler, A, (2004) Living with Spina Bifida: A Guide for Families and Professionals. (Updated Edition. With a New Preface by the Author.) NC: University of North Carolina Press [ISBN 0-8078-5547-2]

Santelli, B., Poyadue, F., & Young, J. (2001) The Parent to Parent Handbook: Baltimore, Md, Paul H Brookes. [ISBN: 1557664978]

Thompson, Charlotte, (2000) Raising a handicapped child: a helpful guide for parents of the physically disabled [Revised and expanded edition] New York: NY, Oxford University Press [ISBN 0-19-513253