

A template for lifelong and day-to-day care

**James Smith
Lifelong Care Plan**

**What about me... A guide for caring
Terry Ryan & Chris Ryan**

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About the Authors

Terry Ryan is the father of Chris who has an intellectual disability. He also has two daughters and two grand-daughters. His family and other families have provided insights into how parents find their way through the demands of managing a family member's disability, providing lifelong care and overcoming personal and family struggles.

Terry has written "What about me..." A guide for caring from a parent's viewpoint of the challenges with lifelong care; it provides practical guidance for parents, siblings and people caring for a person.

Terry has been President of ACTION for People with Disability Incorporated, Chairperson of Manly-Warringah Family and Friends of People with Disability and involved with parent advocacy for many years. He was educated at The University of NSW, Australia and employed in technical and management positions during his career as a surveyor, manager and teacher.

Chris Ryan has mentored many people. He has touched their lives in a quiet and gentle way. Like a teacher, he encouraged his pupils to appreciate the things that really matter. Through his life experience and inspiration he provides an insightful perspective of vulnerability and humility. As a teacher he sees his pupils as raw and precious and through his example polishes them to shine with greater understanding, knowledge and attitude.

Chris has authored "What about me..." A guide for caring by sharing his life story; it articulates a clear understanding of the nature of lifelong care. A story that reminds us that all people need to be loved and nurtured, and with the right support, people with disability can successfully live their lives strengthened by an understanding community and loving care.

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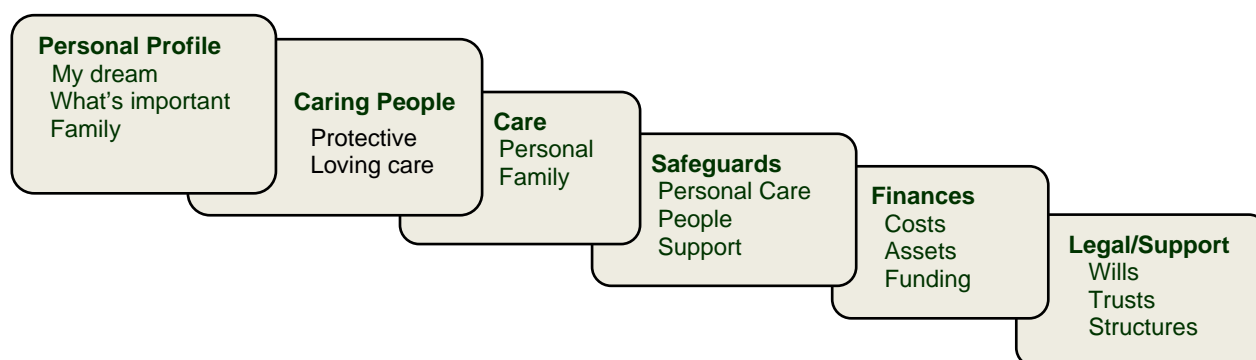
James' Lifelong Care Plan

The purpose of this plan documents James' needs and support arrangements that address his present and future care. The plan provides lifelong and day-to-day arrangements for his care; it includes key points, references to contacts and proven care strategies based on an intimate knowledge of James' needs, temperament and "what works" for him.

The plan primarily focuses on James and identifies associated needs of his sisters Jessica and Jasmin and his parents John and Jennifer. It describes James' care arrangements in relation to his dream, what's important to him and his family.

The plan also describes the roles of caring and protective people who are genuinely connected to his welfare. The role of these people is described in terms of loving care, advocacy and guardianship. These people represent James' best interest in relation to his care, safeguards, financial and legal/support arrangements shown by **Figure 1**.

Figure 1: Lifelong Care



The plan ensures that James and his family are supported with effective and coordinated outcomes; it provides guidelines for the present and future care of James based on inter-related arrangements and not as discrete activities.

The strength of the plan is based on a big picture understanding of lifelong care and a coordinated person-care-financial-legal approach involving:

The caring roles of people have been integrated with legal structures, (personal will, enduring power of attorney, enduring guardianship and trusts) advocacy legislation and principles.

The incorporation of James' lifelong care plan with legal and financial structures provides guidance for executors/trustees as well as defining the primary purpose of these arrangements.

James' Personal Profile**My dream...**

*I dream to be included with people.
I want to feel I belong... to feel a part and be a part.
To be loved and valued.*

What's important to me

I like to walk to the shops or beach or anywhere else to meet and say hello to people. I love dogs and want to know their names. I have a book at home, which contains photos of dogs and their names.

I like to go to the movies, visit my favourite cafés for a cup of tea and a jug of milk and car trips where I sit in the front and listen to the radio. I love music. I tape my favourite music and play it back on my Walkman or listen to my little radio, which has elastic bands stretched around it and a little red light that flashes. Sometimes I have my Walkman and radio on at the same time.

I notice lights that do not work planes and especially helicopters. I like to go to a children's' playground, sit on the swings and chat with the mothers. I watch TV most of the time; I know the names of most Newsreaders and the words of many ads. I can tell the time by the programme I am watching; I love to watch the weather report.

I understand most things but I have trouble explaining what I did during the day; I know what I did but I cannot pull all the words together; it is easier just to say "can't remember".

I can undress myself but need help to dress, especially doing up buttons and shoes. I am not sure about crossing busy streets alone as I can't understand when it is safe to cross. I can feed myself with my left hand. I do try to use my right hand but it has always been a challenge to hold things properly. I am determined to keep trying to use my right hand even though I can't close my fingers with my thumb.

"See I did it" I say, when I use a knife or hold something with my right hand; it has taken me a long time to figure it out, but I am going to keep trying...

James's likes

Getting ready for the bath,
Getting undressed for the bath,
Going out to do an activity,

Fixing lights,
 Watching videos including Mr. Bean,
 Listening to his radio,
 Looking at magazines,
 Praise E.G. "What would I do without you",
 McDonalds,
 Dogs,
 People he has a relationship with,
 Going out to eat,
 Walking to the shops to buy a cup of tea,
 Activities that he will get praise for, and
 Swimming.

James's dislikes

Sitting in the back of the car,
 Authoritative demands, and
 Getting out of bed.

James's favourite activities

James likes music, listening to the radio, watching TV/videos, playing audiotapes, TV, swimming (needs to be watched all the time), walking, shopping and meeting people.

What people like and admire about James

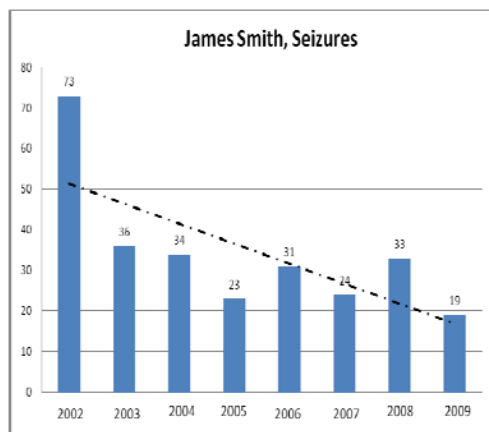


Everybody who has met James has come to know his love of music. His little radio goes everywhere with him; it is more than just a moving celebration of sound. James through his love of music and simple delights has reminded many people of life's basic values and what is really important.

James enjoys talking and being with people. He is gentle, thoughtful and likes to help doing day-to-day chores; he likes to hear people say how helpful he has been.

What people need to know and to do to support James

Diagnosed disability



James has a severe intellectual disability, epilepsy and right-sided hemiplegia mainly to his right hand, arm, leg and right-sided vision as a result of medical complications in his first three months. Presently he is having 2-3 seizures/month. His history of seizures involves differing frequencies, intensities and appearances. Since 2002 seizure frequency has decreased. At times during a seizure he has been known to pull objects and furniture on top of himself. The seizures reflect his well-being. If James is on the verge of

catching a cold he is more likely to have seizures.

James's epilepsy is partly controlled and experiences a range of different types of seizures:

Low level "*background noise*", which James describes as feeling "*shaky*". His eyes may appear to be glazed and lose their sparkle,

Sharp, short "*startled*" jerks lasting a few seconds. These can be triggered by a sharp noise or a sudden light,

Prolonged "*captured*" shaking spasms lasting 10-20 seconds, on occasions he has been frightened, scared, cried or sobbed, and

2-3 minutes gran mal seizures and on rare occasions, continuous seizures at about 10-20 minute frequencies.

James's seizures can affect his mood. The topography of his seizures has changed over time, particularly the appearance and the way his body responds. Before a seizure James may call out, give out a loud noise, moves towards you; his eyes may appear dull or he may seem tired and "*not quite with it*". His speech is often affected when he comes out of a seizure.

Medical

James is incapable of giving informed consent to medical treatment.

Medication	Dose/batch	Morning	Evening	Description
CaltratePlus Tab	1 morn	1		Rose tab
Coversyl 2.5mg Tab	1 night		1	White tab
Epilum 500mg Tab	1 morn, 2 night	1	2	Lilac tab
Lamictal 200mg Tab	1 twice daily	1	1	White tab

As at 20 June 2009

There has been a marked improvement in his cognition and level of understanding. Overall seizure control has improved to the best it has ever been averaging 1-2 seizures per month. His overall quality of life concerns have been carefully balanced with the medication control.

Contacts

Dr. William Willow (GP) ph 9979 5323

Dr. Harold Milner (Neurologist) ph 9875 2210.

Dental

James is not capable of giving informed consent for dental treatment and is unable to receive "normal" dental treatment. He requires anaesthesia for all dental work; he will not open his mouth or sit for prolonged periods of time in a dental chair. The main

concern involves the likelihood of seizure during anaesthesia, gagging and loss of breath.

James is use to having needles in his left arm for blood tests. His left arm is not as sensitive/spastic as his right arm, veins are more visible and larger. He gives blood in a sitting position. The dental procedure must reflect James's "left-sidedness."

James has a natural tendency to gag whenever anything is put into his mouth; cleaning teeth is a challenge. A mouthwash is used to gargle at the end of teeth cleaning at least twice daily.

Contacts

Dr. Dennis Sawler, (Dentist) ph 9906 0640
Dr. Bill Bellow (Anaesthesia) ph 9970 5332
St George Hospital ph 9599 5555
Dr. Martin Green (Anaesthesia) ph 9328 4818
Dr. Carol Sow (Special Needs Dentist) ph 9955 5623

Personal needs

James requires 24-hour care. He needs a balanced diet supplemented with appropriate minerals, vitamins and regular exercise. Without active care, his wellbeing can be adversely affected by:

Cold and flu infections can trigger epilepsy,
Low nutrition can affect his mood and ability to cope,
A passive lifestyle involving lethargy, loss of self-esteem and confidence, and
Not being involved with other people and community activities.

James is often slow to eat in the early morning and is more likely to want to eat mid morning. If he has not eaten he can become moody and this will affect his behaviour. If James has an early morning start it is suggested that he is given fluids such as juice/tea/ banana smoothie. When James has time, he likes porridge or sultana bran covered with yoghurt and banana.

James has no known allergies or conditions and does not have asthma.

James can become constipated maybe due to his diet. For this reason, regular prunes and fruit have helped to regulate his bowel movements.

James's mood can change when he has had little sleep or has undertaken demanding or strenuous exercise or had a seizure.

When James is starting to become sick, his seizure activity usually increases. It is suggested that vitamin C will help manage his sickness as well as helping to manage his stress levels.

James is generally healthy and is eating and sleeping well. He needs to have regular exercise especially walking and swimming. He has problems with swallowing and keeping his mouth opened without gagging, particularly evident when his teeth are brushed.

James will take his medication together with a cup of tea or juice.

Mealtimes

James can eat meals independently using the appropriate utensils with his left hand. He has little use of right hand. He may sometimes need reminders about appropriate behaviour at the dinner table and the speed at which he eats.

Dressing

James is independent in some areas of dressing however needs help selecting and changing clothing, putting on his socks and shoes and doing up buttons and shoe laces.

Toileting

James will use the toilet. He needs physical assistance to wipe his bottom after a bowel motion and reminders to flush the toilet and wash his hands.

Bathing

James can bath fairly independently. However, may need physical assistance to regulate the water temperature, he also needs verbal reminders to wash all areas of his body and help with washing his hair and toweling down.

Grooming

James needs physical assistance in all areas of grooming including shaving, applying deodorant, washing his hair and brushing his teeth and hair.

Domestic Skills

James needs assistance or does not participate in all household/ living skills including meal preparation, washing clothes, cleaning, setting the table. With encouragement he will complete some tasks. He will also put away his belongings such as his bag and magazines if asked.

Community Access

James needs full-time supervision in the community; he has little or no safety skills such as stranger awareness and road crossing. However, he is able to identify himself by name.

Recreation

James will undertake some recreational activities alone including watching a video and listening to music. He enjoys going to the movies, going out to dinner, anything 1:1, swimming, walking, talking to people in the community, seeing animals especially dogs.

Literacy/ Numeracy

James has no reading and writing skills.

Sleeping

James is generally a good sleeper, goes to bed about 9pm, and gets up about 7.30. He can be difficult in getting him up. Juice or a cup of tea, followed by banana will usually get him started.

Emotions

James does not openly discuss his emotions, the people who know James well can interpret the non-verbal communication that James displays including body language, actions and facial expression to ascertain how he is feeling or what his needs may be. James will smile proudly when he feels he has done something well. He is an affectionate person who enjoys touching and being touched by others. James is often over friendly with people in the community he does not know.

Behaviour

James's mood can fluctuate. He can be happy and jovial at times and at others negative. His behaviour is affected by his seizure activity, tiredness, diet and health. When James is happy he will smile, joke, tickle and be affectionate. He is generally less demanding when he is happy. James is unable to express his negative emotions in an appropriate manner. When he is angry or frustrated he may swear, mumble or engage in aggressive behaviours towards property, objects or others. James is fearful of unknown activities, if he does not know the expectations of him or the expectations placed on him are too high for him to meet. He does not have the verbal skills to express his concerns and may express his concerns through action.

James has engaged in the following behaviours: swearing, grinding teeth, spitting and obsessing over electrical lights that are not working.

*A major **key** in managing James's behaviour is through a caring, responsive and non-authoritarian manner and taking into account James's state of epilepsy, tiredness, eating and sickness.*

James needs to be approached in a positive manner. It is good to smile and use a positive tone of voice. If time is taken to really understand and connect with James, behaviour management techniques are more effective.

James loves to joke and the use of humour as a distraction technique is a useful "tool" in converting a challenging situation into a positive outcome.

If James is refusing to go to bed offer: a magazine, read to him, put music on for him to listen to when he gets into bed.

If James is refusing to get up in the morning you can talk to him about something he may be doing that day, turn his radio on, talk about socks he could wear E.G. "You could wear the socks with the dogs on it", ask James if he wants to take a preferred item, ask him what he would like to take for lunch.

If James is refusing to undertake a task, give him some time and re-approach.

Acknowledge James when he makes a choice, say “fantastic” or “thanks.”

Choices are presented one at a time, to elicit a Yes/No response. James needs time to think about it before answering. Then present the next option. If one of the options is highly preferred, present the preferred activity first E.G. would you like to go swimming or read a magazine to discourage James from always selecting the last option.

The nature of people who support James best

Friendly and non-authoritarian manner and open nature.

Who can understand and make allowances for James’s vulnerability.

Who can promote James’ positive qualities.

Who can encourage personal interaction and build a relationship.

How James communicates

James is verbal and communicates his meaning by physical direction (taking your hand), saying one word or a short sentence. He has a wide vocabulary but often has trouble stringing words together to make a sentence. He often uses inappropriate or repetitive language to gain attention or to interact when he does not know what to say. He may also use his radio or other items such as his rubber bands as a topic of conversation with the people he meets. James is good at communicating his needs/wants at times E.G. “I want to go to bed, I want to have a shower” and generally asks when he wants something.

Things to figure out – things we still need to know

Long term care accommodation, particularly aged care.

Day program to be extended from three days to four days.

Maintaining varied and regular exercise activities.

Leisure and social activities.

Lifelong care safeguards: keeping up with the rising cost of care, financial structures, trust, trustees and legal arrangements.

**How people will
care for James**

The roles of the *Trustees/people*¹ in providing care of James include having a genuine connection with him based on an understanding of personal needs in relation to: nurture, quality of life and living a good life.²

Trustees/people to act as strong protectors by managing financial affairs, making beneficial changes, providing loyalty, being committed for the long-term, understanding specific needs and associated care and if required, represent James with little or no conflict of interest.

Trustees/people will ensure that the care of James meets his physical, emotional, educational, economic and social needs by:

- Sustaining and protecting his rights,
- Actively seeking to include James in community activities and lifestyles,
- Growing James' status as a valued person involved with valued roles, and
- Ensuring James is treated with respect and dignity.

Trustees/people will provide value through their leadership, managing relationships and if required, being creative by:

- Rectifying unfavourable circumstances,
- Being concerned with James' holistic needs, and
- Representing James' best interests.

In exercising their powers *Trustees/people* will:

- Have regard to James' best interests as their paramount consideration,
- Have regard to the wishes expressed in the latest version of James' Lifelong Care Plan or similar document prepared James' parents with respect to his life, needs and care,
- Assist James to develop his abilities to the maximum, to be as independent and live a normal life as possible that includes participation in mainstream activities and lifestyles,
- Do their utmost to advance and reflect James' status as a valued person, to be treated with respect and dignity,
- Endeavour to protect James from neglect, abuse and exploitation,
- Take into account James' wishes so far as such wishes are discernible,

¹ Trustees/people identified in the Legal Section of this Plan

Consider from time to time the advice of his family, carers and professionals and other persons involved with James, and
 Take into account the effect of the exercise of their powers on any social security benefits, taxation or duty of any trust or James.

How care will be provided

James

James' physical, emotional, educational, economic and social well-being will be reflected in care environments that uphold his rights as a valued person and treats him with respect and dignity.

James' care environments will reflect the following outcomes:

Addressing and rectifying situations where he may be disadvantaged,
 Striving to minimise conflicts of interests,
 Engaging in vigorous action that positively resolves short or long term issues,
 Maintaining fidelity with him in any disadvantaged situation,
 Supporting his endeavours in developing a valued social role, and
 Encouraging community participation.

James' care accommodation will include the following considerations:

Safety, disability management, nutrition, exercise, quality of life and living "the good life",
 Quality, experience and constancy of carers,
 The "chemistry" between James, residents and carers,
 Physical layout of the home,
 The practical and positive support of carers and other people,
 A competent caring house manager is essential. A good house manager backed up by competent staff is the single most important factor in running a successful supported accommodation care arrangement,
 Providing daily care involving: personal care, dressing, bathing, meal preparation, toileting, safety, medication, behaviour, transport, household activities, shopping, community involvement, social outings and other activities associated with the specific needs of the residents,
 Providing a positive amicable living arrangement where residents, carers or facilitators are compatible,
 Encouraging appropriate independence, and
 Actively involved with social and community activities.
 The focus for carers includes: genuine connection with James and his needs, providing individual choice and purposeful external activities.

² Sharing a life with other people that include: a home, having friends, security, personal development, decision-making, community involvement, good health, making a meaningful contribution and happiness.

Area of care	Focus	Activities
Accommodation	Living Skills Safety Awareness Fitness and stamina	Make a cup of tea/sandwich Dressing, bathing, combing/washing hair Road crossing Fire/electricity awareness Walking dogs Walk to shops Swimming Excursion
Day Program	Group interaction Community access Work	Supporting/working with others Shopping, social, leisure Factory: 1 to 1 support Paper run
Respite care	Personal care	Epilepsy management Safety
Family home	Personal, social	Dressing, bathing, toilet Social behaviour Eating

James requires full-time care accommodation as shown in **Table 1**.

Table 1: Care Accommodation Options

Type	Suitability <small>* James requires full-time care</small>	Description
Group Home	Yes	4-6 people with disabilities living together in accommodation owned or leased by a service provider who manage the running of the home and care for the residents on a full-time basis.
Semi-independent	No*	2-3 people with disabilities living together in accommodation that may be owned by a service provider who also provides part-time support.
Co-residency	No*	2-3 people living together in accommodation that may be provided by a service provider. At least one of the people does not have a disability and provides support and companionship to other residents in exchange for discounted rent or board.
Housing with support	No*	A joint venture between agencies where housing and support is separated. The person with a disability is provided accommodation managed by a housing agency and a service provider manages the daily support.
Equity housing	Yes	Shared ownership of a home that is designed to meet the special needs of the residents. The residents “pool” their support and resources. A service provider manages daily support.
Supported living	No*	1-2 people with disabilities own or lease the home by themselves or on their behalf. A service provider manages the daily support. This option can involve accessing a range of services that may include general community services, disability support services, family, friends and neighbours.
Congregate care	No*	10-20 people with disabilities living together in an accommodation cluster (E.G. Villa homes) owned or leased by a service provider who manages the home and care for the residents on a full-time basis.
Family home	Yes	Independent/supported living area. Family care will be offset with service provider services that may include: respite, community access, in-house disability support, social and personal support network.

James' personal safeguards

James' personal safeguards include: personal care, caring and protective people, respite care, short/long term care accommodation, support network, education, work, social and specific needs.

James' safeguards recognize his vulnerability and the need for lifelong support. All arrangements need to be periodically reviewed in relation to changing personal needs and major changes involving daily needs, family/lifestyle circumstances and care accommodation.

Personal care ³	James' personal care has been described in the <i>James' Personal Profile</i> of this Plan.
Caring and protective people	James' parents John and Jennifer Smith, sisters Jessica and Jasmin and The Evergreen Association.
Respite care ⁴	The Evergreen Association provides respite care as part of the Group Home residential service.
Care accommodation	Suitable options: Group home, Equity housing and Family home as mentioned in <i>Care Accommodation Options</i> of this Plan.
Support network	James' immediate family, friends and The Evergreen Association. Informal network: Forest Way/Glenrose Shopping Centres, and the Northern Beaches Area.
Education	Personal safety, health, domestic skills and community access.
Work	Purposeful work, high social interaction, 1:1 supervision.
Social	Community activities, lifestyles and interaction with peers, friends and co-workers. See <i>What's important to James</i> of this Plan.
Specific needs	James' needs include: personal wellbeing, safety supervision at all times and quality social interaction. See <i>James' Personal Profile</i> of this Plan.

³ Relationships, disability management, social, work, activities

⁴ Regular planned respite support

James' Parents: John and Jennifer

John and Jennifer needs include the following considerations:

- Better management of their personal and family struggles with providing full-time care,
- Development of a support network involving their extended family, friends, and professionals,
- Effective home help,
- Guidance and support with James' disability and his care needs,
- Engagement with other parents in similar circumstances,
- Respite care on a regular planned basis,
- Long and short term financial planning,
- Balancing family needs,
- Regular exercise, and
- Stress management.

James' Sisters: Jessica and Jasmin

Jessica and Jasmin need include the following considerations:

- Specific understanding of their circumstances and emotional support,
- Contact with other siblings: exchange of experiences, and future care of James.

What are the financial arrangements?

James

To effectively address James' needs he requires a team of people who play a role in providing lifelong care. The support team is likely to include: parents-adult siblings-family members, carers, medical, legal and financial professionals. All professional advice must be determined in context with this Plan based on supporting James's personal needs and arrangements that ensure lifelong care as well as all his family members.

The trustees must operate with an understanding that care needs will change for James and his family members and as such, Trustees must engage with appropriate members of James's team at times when changes need to be considered in relation to financial considerations.

Care support	James	Arrangements	Financial	
			Income \$PA	Expense \$PA
24 hour care	Yes	Group home care depends on private - DADHC funding. Evergreen Association's group home running costs	50,000	8,829
Advocacy	Yes	Depends on availability and issues	0	0
Daily living	Yes	Post School Options and Respite Care - DADHC funding	15,000	0
Education	No	Skills, safety, hygiene...	0	0
Financial	Yes	Bank account - interest	3,000	0
Government benefits	Yes	Disability Support Pension and allowances Rebates: Dental, Medical ...	18,409	0
Home modifications	Yes	Shower rails, safety, ramp...	0	1,000
Medical, Dental, Therapies...	Yes	Visits, check-ups, procedures...	0	1,000
Parent support	Yes	Support: advice, guidance, self-care	0	0
Personal care	Yes	See <i>James' Personal Profile</i> of this Plan	0	17,450
Specialised transport	No	Modification, special purpose	0	0
Legal, Accounting, Financial support	Yes	Personal wills, power of attorney, enduring guardianship, trust and safeguards. Professional fees: Solicitor, Accountant, Financial Adviser...)	0	3,000
Totals			86,409	31,279

Financial support for James must be holistic and not limited to managing the assets of the Smith Family.

The Planning for James's needs is based on an understanding of the relationship between James, his parents and siblings, The Evergreen Association (Service Provider) and carers, as well as the financial relationships that operate between The Evergreen Association, Department of Disability and Home Care (DADHC), Centrelink and the financial support provided by the Smith Family shown by **Table 2**.

Table 2: Total Cost of Care

Financial support	Expenses \$PA	Income \$PA	Funding \$PA
Financial			
Trustee bank account: Smith family members. \$50,000 @ 6% PA		3,000	
Care accommodation			
DADHC Group Home funding			50,000
Income: James' Disability Support Pension (\$512.10), Pension Basic Supplement (\$17.80), Pharmaceutical Allowance (\$5.80), Rent Assistance (\$100.95), Mobility Allowance (\$71.40), Total \$708.05 per fortnight		18,409	
Evergreen Association: Board and lodging (\$69.60), White goods (\$10.00), Food and Bills (\$260.00), Total \$339.60 per fortnight.	8,829		
Personal care			
Family home: clothing, shoes, other needs...	2,000		
Medical: GP, specialist	1,250		
Personal health insurance	1,200		
Dental: Yearly checkup	1,000		
Special needs: therapy, 1:1 care support...	10,000		
Contingency	2,000		
<i>Subtotal</i>	<i>17,450⁵</i>		
Activities			
Post School Options and Respite Care (DADHC funding)			15,000
Education: Childcare/School/TAFE – support, education, travel...	5,000		
Social, leisure, fees, travel...	2,500		
Work, travel...	400		
Totals	\$34,179⁶	\$21,409⁷	\$65,000⁸

⁵ Indicative costs; usually paid by families

⁶ Indicative total cost; each family circumstance and support arrangements are different

⁷ Indicative income; depends on family circumstances and pension/allowances eligibility

⁸ Funding varies for each individual and support arrangements

Disability Support Pension

Evergreen provides James's care accommodation. James receives the Disability Support Pension (DSP), paid by Centrelink, which largely pays for his care accommodation. The high cost of providing care for James depends on Evergreen also receiving funding from Department of Disability and Home Care (DADHC). The day-to-day expenses rely on income from the Smith Trust and his parents.

Given the high cost of care, it is vital that James maintains access to the Disability Support Pension (DSP). DSP is means tested by Centrelink and the management of the Smith Trust should only be done in consideration of the impact on James's DSP. It is possible that mismanagement of The Trust would lead to James being ineligible for the DSP. In this event, the assets of The Trust would be drawn upon very heavily. In the long run James's total income would fall and this may lead to a lower standard of care.

Special Disability Trust

The Trustees have a significant responsibility for making decisions, which can impact James's overall financial position, and therefore impact on Evergreen Association's ability to fund James's needs if the DSP is reduced or no longer available. (It should be noted that the increasing cost of providing health care services rise at a faster rate than the general measure of inflation, the consumer price index). Given the current high level of reliance upon Evergreen's funding of James's long term care accommodation, day-to-day care, and the risk that that this funding may not always be at current levels, it is critical that the Trustees maximize James's DSP and the assets of The Smith Trust.

James is regarded as severely disabled and is eligible to take advantage of the proposed Special Disability Trust, which is being reviewed by the Australian Government after its unsuccessful introduction. The trust arrangements allow up to \$532,000⁹ of trust assets and together with its net income will not be treated as an asset or income in determining James's DSP by Centrelink.

The characteristics of a Special Disability Trust involve:

- Being '*protective*' in nature,
- One principal beneficiary (i.e. the person for who the trust is established),
- The beneficiary must have a '*severe disability*',
- Meeting accommodation and care needs of the beneficiary,
- A trust deed that follows the model trust deed,
- An independent trustee or more than one trustee,
- Compliance with the investment restrictions,
- Annual financial statements, and
- Independent audits when required.

This Trust will not be suitable for all families as each circumstance is different.

⁹ Special Disability Trust Assets are indexed each year

Financial Structures

The financial assets are managed in a way to produce revenue for care/lifestyle support arrangements. James he can be easily exploited by people who may seek to take advantage, accordingly assets will be managed by a Trust. The Trustees will represent James' best interests with making financial arrangements and payments.

The Trustees are required to periodically review the effectiveness of the financial structures in relation to changing needs and if required, change the arrangements shown in **Table 2**.

Table 3: Financial Structures

Entity	Purpose	Details
The Smith Trust	Discretionary Trust Principally provide lifelong care of James, John, Jennifer, Jessica and Jasmin Smith. Beneficiaries identified in the schedules of the Deed of Trust. To receive and distribute income through investment	Trustees John, Jennifer, Jessica, Jasmin Deed of Trust 11 November 1999 TFN 43 444 222 Building Society Investment account BSB 111 000, Acc#712617444
Special Disability Trust	Single beneficiary Trust Beneficiary James Smith	Trustees John, Jennifer and Stephen (Independent Trustee) Deed of Trust 17 May 2009 TFN 54 555 333 Building Society Investment account BSB 222 333, Acc#712617555
John Smith Superannuation	Self Managed Superannuation Fund Provide for Jennifer, Jessica, James and Jasmin	Superannuation Service Member number M111 222
Smith Bank Account/s	Joint Trustee Account Day-to-day expenses Manages cash flow from Trust/s	Trustees John, Jennifer Building Society cash account BSB 222 444, Acc# 3456 78999

**What are the legal
and support
arrangements?**

Legal and support arrangements need to consider family circumstances, individual family member's needs and James' care arrangements in relation to Personal Will/s, Trust/s, Trustees, Guardianship, Advocacy and Property.

Table 4: Legal and Safeguards

Personal will/s	
Executors, Trustees	Executors, Trustees Surviving Spouse John/Jennifer Smith, Jessica and Jasmin Smith
Beneficiaries	Beneficiaries Surviving Spouse (John/Jennifer Smith), James Smith, John and Jennifer Smith, Jessica and Jasmin Smith and their families.
Testamentary	Testamentary Distribution and protection of assets: equal share of assets with surviving spouse (John/Jennifer Smith), Jessica, James and Jasmin. Testamentary Trust: to describe descendant arrangements. Appointment of The Smith Trust Directors. Executors/Trustees roles to be defined – their roles are described in <i>How People Will Care For James</i> of this Plan. Lifelong Care Plan: James' lifelong care is described in this plan; it will be included with the testamentary intention as it qualifies and strengthens the will/s and provides guidance for Executors/Trustees; it is a critical that John and Jennifer pass on their knowledge and explain James' support arrangements.
Capability, Independence	James' capability/independence James is/not capable with making a personal will and appointing Trustees/Guardians for his enduring power of attorney and enduring guardianship.
Trust(s), Arrangements	
Lifelong Care	Lifelong Care Plan The Plan forms part of all Trust Deeds; it describes the purpose of the Trust/s and responsibilities of the Trustees; it substantiates lifelong care arrangements and provides guidance for Trustees.
Discretionary Trust	Smith Family Discretionary Trust Trustees: Surviving spouse John/Jennifer, Jessica and Jasmin Deed of Trust must include James' Lifelong Care Plan Multiple Beneficiaries: James, John, Jennifer, Jessica, Jasmin. Descendent arrangements: consider "control test" in relation to

	primary/shared beneficiaries and appointment of Trustees.
Special Disability Trust	James' Special Disability Trust ¹⁰ Trustees: Surviving spouse John/Jennifer, Jessica, Jasmin and Stephen (Independent Trustee) Sole Beneficiary: James Deed of Trust must include James' Lifelong Care Plan Be <i>protective</i> in nature as described in James' Lifelong Care Plan Provide for accommodation and care needs for James Comply with the model trust deed, investment restrictions and provide annual financial statements.
Enduring Power of Attorney	Financial authority Access to financial accounts: John, Jennifer, Jessica and Jasmin Smith.
Trustee Bank Accounts	Bank accounts Trustee account, single/multiple people acting as Trustee for James and other family members who may be joint/single account signatories.
Living will	A voluntary statement by James/John/Jennifer outlining the conditions of medical care that James prefers for a given situation prior to requiring care.
Guardianship	
Enduring Guardianship	Enduring Guardianship John and Jennifer responsible for personal and lifestyle functions for James subject to his capability to provide consent.
Legal Guardianship	Legal Guardianship Responsibilities for accommodation, medical/dental, behaviour management and other areas in relation to specific needs and personal well-being. Legal guardianship may be considered when there is a significant threat to James' well-being.
Advocacy	
Support, information	Advocacy support Guidance and support for family members as required when dealing with services and contentious areas requiring information and objective support with James' best interests.
Property	
Family Property	Sale conditions Certificate of Title covenant/caveat setting out conditions for the sale/use of the family home/property safeguarding James' lifelong care.

¹⁰ Special Disability Trust under review, Australian Government