

Information for Care Givers of Young Participants

The Lifetime Support Scheme supports people of all ages who are very seriously injured in a motor vehicle accident in South Australia, including children and young adults.

The Scheme is run by the Lifetime Support Authority (LSA).

LSA Service Planners work closely with LSS Participants and families to coordinate treatment, care and support services to make a positive difference to their recovery and independence.

This Information Sheet offers practical tips for families as carers and includes links to supports within the community.

What happens in hospital?

While your child is an inpatient, you'll get updates and advice from the treatment team of hospital staff.

An LSA Service Planner will work closely with the treating hospital team, and is there for you, to explain the scheme and the supports available.



When the time is right, discharge planning will begin. This means discussing what a future at home might look like and what you'll need to care for your child.

Conversations and regular planning continue at home and for as long as your child is an LSS Participant.

How can I learn more about the Scheme?

The LSA website offers information sheets to help you learn more (<u>lifetimesupport.sa.gov.au</u>) and includes information on what the LSA will fund.

We fund necessary and reasonable treatment, care and support, such as:

- medical treatment (including doctor's appointments and pharmaceuticals
- dental treatment

- rehabilitation including physiotherapy, occupational and speech therapy
- ambulance transportation
- respite care
- attendant care and support services including personal care and domestic services
- assistive technology (e.g. wheelchairs, mobility aids, beds, respiratory equipment or communication devices)
- prosthetic and orthotic devices
- education and vocational training
- home, motor vehicle and workplace modification.

Talk with your child's Service Planner to understand if a service is funded by the LSA.

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How can I learn more about the injury and prepare for going home?

Having your child return home is a big step.

Surround yourself with family and friends, and relevant medical and other health professionals (including your child's LSA Service Planner).

This is vital in the first few weeks. These people support you and your child and can help you make informed decisions on the supports required.

Try these tips:

- learn about your child's diagnosis, treatment, and management options. Take notes or create a diary that includes upcoming appointments and any questions you want to ask
- use the internet wisely for information, knowing it's not always accurate. Discuss queries with health professionals or your LSA Service Planner
- know how to contact the health professional for appointment changes or after-hours concerns. Keep phone and email contacts handy
- find a GP you can talk to if you don't have one. This helps if you or other family need support services to adjust to what has happened
- you'll begin to instinctively observe and know your child's needs, state of mind and level of discomfort or pain. Never underestimate your gut feeling if you think something may be wrong

- if your child can't talk, become their 'voice' when dealing with others. For a young child, you'll be their 'voice' regardless
- if your child can communicate, encourage them to play a role in treatment and rehabilitation planning.

How can I care for myself?

This is a major change to your life. While everyone is different, these tips have been proven to help.

- set reasonable expectations of yourself and what you can achieve
- find time to enjoy outings with friends, family or your partner.
 It's essential to your self-care
- if people want to help, say yes!
- have frozen meals at home or take advantage of home delivery (within your family budget)
- get disabled parking permits (if applicable) to make transport easier.

Is there support available for siblings?

Your child's injury can be traumatic for brothers or sisters, especially if they don't understand what is happening.

They can sometimes overhear information and make the wrong assumptions about what is happening.

Share information about the injury at a level they can understand.

Help them learn about any special care needs or they may think this care is about being the 'favourite' and feel left out.

Some common feelings and experiences of siblings include guilt, embarrassment, fear, pressure to achieve, confusion, anger or jealousy.

Many of these feelings can continue as adults, which means siblings need the chance to express their feelings and the reality of their experience.

If you believe your other children are finding it difficult to cope, there are organisations that can help.

How do I help my child adjust and just be a kid?

Remember they are a child first. If rehabilitation is getting too much, take some time out and discuss options with health professionals and your child's LSA Service Planner.

- focus on what your child can do, not what they can't. List the things they've achieved this week and stick it on the fridge door. And if your child reaches a goal, don't hesitate to celebrate!
- find activities that suit your child. A sports club or community program helps build confidence, self-esteem and make new friends. This helps as they learn to adapt to a life with their injury
- help rebuild friendships. Ask friends over to enjoy a movie or encourage your child to send messages/emails. This helps your child stay in touch and even make new friends.



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What help is available to help my child start/return to school?

Planning will start early and the LSA will fund an assessment with a specialist who will make recommendations based on your child's needs.

The Education Department can plan for extra support for children with learning difficulties, health conditions or care needs which impact attendance and participation at school or preschool.

There will be discussions that will include you, the school and your child's LSA Service Planner. These discussions will also include health professionals who are working with your child.

If you feel the time is right, talk to your child about school early to help reduce any fears and anxiety. It helps to include and ask your child for their ideas during planning:

- what plans and hopes do they have for their school life?
- how would they feel about going to school part-time and returning gradually to full-time?
- would they feel comfortable with the one-on-one support of an integration aide?

As a team you'll discuss the challenges ahead, to create a program that meets your child's needs.

During school years there is also discussion about the future. This might include study, or work, or the need for ongoing support services that maximise your child's independence as they get older.

How can I support my child to optimise their independence?

The LSA uses decision making steps to help you and your child make a move towards independence over time.

There is no set age for this to occur, and we encourage families to do this progressively, prior to your child reaching their adult years (18 years).

Decision making steps move from no involvement where you are your child's voice through active involvement to extensive involvement where you support your child to give feedback and make suggestions.

- a young child or a person with complex needs start at a low step and some may find it challenging to participate at a higher step
- participation may be different in different contexts (e.g. high level when talking about fun activities but lower level when discussing treatment)
- most children can be enabled to participate over time.

EMPOWER ME



You are empowered as a participant to give feedback, decide what's needed and/or suggest plan actions and targets in line with your views, strengths and interests. Family and others are involved in a supportive role to provide further clarity and insight.

ENGAGE ME

While family and others might start a conversation, you are engaged and involved. As a participant, you ask and answer questions. You contribute to making decisions, to create a plan in line with your views, strengths and interests.

SUPPORT ME

Family and others share your views, strengths and interests using direct quotes or previous choices. They'll ask questions to find out more. As a participant you're consulted, helped and can comment on decisions made for you.

ABOUT ME



You are talked about, and family and others make decisions for you. They should use their judgment to consider your views, strengths and interests. As a participant, you might not be making choices or speaking for yourself.



DECISION MAKING STEPS

What happens as my child becomes an adult?

A part of getting older and growing up is a transition from a paediatric treatment team to adult services and specialists.

This occurs at 18 years, when medical and other health professionals will begin a transfer of services.

Your LSA Service Planner can support you and your child during this change to make it as smooth and stress free as possible.

As a lifetime scheme, the LSA will continue to support your child through adulthood.



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General Resources and Supports for Parents

Lifetime Support Authority

Phone: (08) 8463 6131

Web: lifetimesupport.sa.gov.au

Injuries

Spinal Cord Injuries Australia

Phone: 1800 819 775

Brain Injury SA

Phone: (08) 8217 7600 or 1300 733 049

Can Do4Kids

Phone: (08) 8100 8200

Parenting

Child and Family Health Service (CAFHS)

Parent Helpline: 1300 364 100

Phone: 1300 733 606

Family Advocacy Inc.

Phone: (02) 9869 0866 or 1800 620 588

Families Growing Together (SA Government)

Web: dhs.sa.gov.au

Relationships Australia (SA)

Phone: (08) 8216 5200 or 1800 182 325

Raising Children

Web: raisingchildren.net.au

Parent Helpline

Phone: 1300 364 100

Parenting SA

Phone: (08) 8303 1660

Caring Role

Carers SA – Supporting Family Carers

Phone: 1800 422 737

My-Time: For Parents of Children with Disability

Web: mytime.net.au

Family Day Care Business and Customer Support Centre

Phone: (08) 8343 6533 or 1300 551 890

SA Disabled Persons' Parking Permits

Service SA

Web: service.sa.gov.au

Companion Card Program

Phone: 1800 667 110

Emergency Medical Information Booklet (EMIB)

Web: emib.org.au

Grandparents For Grandchildren

Phone: (08) 8212 1937

Siblings

Livewire

Web: livewire.org.au

Big Brothers and Sisters Australia

Phone: 8203 9400

Siblings Australia Inc.

Web: siblingsaustralia.org.au

Please note: resource listing is correct at time of writing this document (March 2023).

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Mental Health

Skylight Mental Health

Phone: (08) 8378 4100

Child and Adolescent Mental Health Services

CAMHS Southern Metro Phone: (08) 8326 1234 CAMHS Northern Metro Phone: (08) 8252 0133

Kids Help Line

Phone: 1800 55 1800 (Counselling Line)

Lifeline: 24-hour counselling service

Phone: 131 114

SANE Australia

Phone: (03) 9682 5933

Helpline Phone: 1800 187 263

Education

Special Education Resource Unit (SERU)

Phone: (08) 8235 2871

Student Support Services (SA Government)

Web: education.sa.gov.au

Student Pathways (SA Government)

Web: studentpathways.sa.edu.au

Department of Education

Phone: (08) 8226 1000 or 1800 088 158