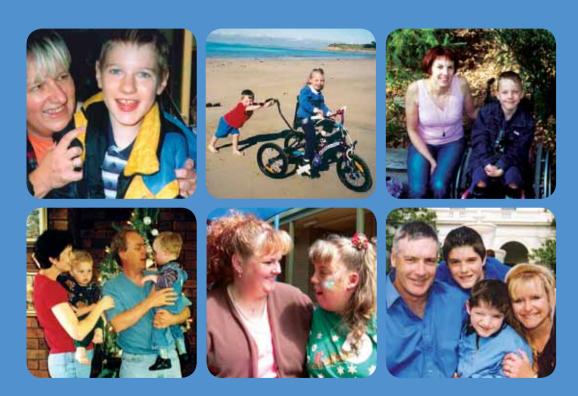
# Helping You and Your Family

Information, support and advocacy for parents of children with a disability in Victoria

3rd edition 2013



#### **Association for Children with a Disability**

We provide information, support and advocacy to families who have a child or young adult with any type of disability or developmental delay across Victoria.

Our Association is run by parents and siblings so we know what it means to have a family member with a disability. We understand issues from a family perspective.

Our services include free telephone information and advocacy support for families.

Our member magazine, NoticeBoard, includes family stories that are a great source of strength and inspiration for other families and professionals who work with families.

Association for Children with a Disability Suite 2, 98 Morang Road Hawthorn VIC 3122

Phone 03 9818 2000 or 1800 654 013 (rural callers) Fax 03 9818 2300 Email mail@acd.org.au Web www.acd.org.au

#### Language interpreters

If you need a language interpreter to access our service, call the Translating and Interpreting Service on **13 14 50**. Tell the operator your preferred language and that you want to speak to the Association for Children with a Disability on **03 9818 2000**. This is a free service.

# Helping You and Your Family

Information, support and advocacy for parents of children with a disability in Victoria

3rd edition 2013



#### **Acknowledgements**

Helping You and Your Family: Information, support and advocacy for parents of children with a disability in Victoria, 3rd edition 2013.

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This version of Helping You and Your Family is revised from our 2nd edition 2009, that draws on a previous booklet of the same name published by the Association for Children with a Disability in 2000 and another publication, Helping Parents Help Themselves, published in 1991. Thanks to all the parents who contributed to this version and the earlier publications.

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#### Your feedback

We welcome your feedback on this booklet and any other aspect of our service.

Send to: Association for Children with a Disability Suite 2, 98 Morang Road Hawthorn VIC 3122

Phone: 03 9818 2000 or 1800 654 013 (rural callers)

Fax: 03 9818 2300 Email: mail@acd.org.au

#### **'Disability'**

The word disability means different things to different people. Some people and organisations try to avoid using the word 'disability', preferring instead phrases such as 'special needs', 'additional needs' or 'children of differing ability'.

In this booklet we use the word disability. We understand and respect that some people prefer not to use the word disability to describe their child.

Disability doesn't have to be a negative word. It's important to acknowledge and understand the difficulties and limitations that disability can place on your child and family. It's also important to focus on your child's strengths and abilities.

We might use different words to describe our situation, but what brings us together is a shared belief in our strengths as parents, as we strive for what is best for our children and families.

## Introduction

This booklet has been written by parents of children with a disability.

We are a unique and diverse group of people with a wide variety of experiences and knowledge.

As parents of children with a disability, we share a common bond. We also face many challenges.

We have written this booklet to help you and your family by:

- Sharing information about other parents' experiences, ideas and suggestions, and
- Giving you links to information about services and support.

By sharing information and supporting each other, we not only help our own family but others as well.

When we draw on our strengths as parents, we grow stronger together.



"I have been surprised to discover how many families of children with a disability there are in my local community."

## Diagnosis



"That consultation when my son was officially given his diagnosis seemed to be happening in slow motion, like in a movie. I walked out of the room in a daze and then when I got to the car, I burst into tears."

Parent and family experiences of identifying a child's disability vary greatly.

Some conditions are evident at birth or soon after. Others can occur as the result of an accident or illness.

Identifying a child's disability and getting a diagnosis is often a gradual process that occurs over many months or years.

For some children, a clear diagnosis of a specific condition or disability (or multiple disabilities) is possible.

For others, the diagnosis of a specific condition may not be possible, or may depend on tests and observations in future years.

#### **Mixed emotions**

The process of getting a diagnosis is often a traumatic and stressful time. It can be very emotionally challenging for parents and other family members.

You may experience: fear, confusion, isolation, loss, grief, hope, shame, anger, blame, despair, exhaustion, relief, love, protectiveness and more.

#### You're not alone

The range and depth of emotions we experience is often difficult for us, and those close to us, to understand.

Please remember that you are not alone. Other parents and support services are available to help you and your family during the difficult times.

## **Emotions**

The emotional ups and downs we experience are often difficult for others to understand.

For many of us, our emotions are never far from the surface, especially when we find ourselves in a situation that accentuates our child's differences.

We all cope and respond differently to the challenges we face. There is no right or wrong way. Every child and every family situation is different.

Being able to discuss problems, experiences and feelings with other people who understand can be beneficial.

Some parents find it helpful to write down their thoughts, feelings and emotions. Others like to get involved in practical activities.

#### Seek support if you need to

The different ways in which people respond can sometimes cause tension between partners, other family members and friends. Seeking advice and support at this time can benefit all family members.

Sometimes it can be as simple as understanding the different ways that women and men tend to approach difficult issues.

#### **Celebrate achievements**

It is also important to celebrate and appreciate your child's achievements and successes, no matter how big or small.

With all the strong emotions that come with having a child with a disability, it can sometimes be hard to maintain a positive outlook.

Despite all the challenges, you and your family can still experience plenty of joy and happiness.



"From day one it has been a real rollercoaster of emotions. We try to enjoy the ups when they come and ride through the downs as best we can."

## Family and friends



"I think family and friends wanted to help us, they just didn't understand the sort of help we needed from them. Looking back now, I wish I could have found a simple way of letting them know."

# Disability can challenge our family and friends.

For some of us, family and friends may have been a great source of support from day one, asking what they can do and offering practical help and understanding.

For others, friends may have drifted away and family members become more distant.

Within your extended network of family and friends, you will soon discover who is able to support you during the stressful times.

Keep in mind that it may not be easy for family and friends to understand your situation. They could be so overwhelmed that they just don't know what to say or do.

#### Little things can make a big difference

Sometimes people don't realise that there are little things they can say or do to help, or they may not know enough about your situation to understand the support you need.

Admitting to yourself and others that you need help is not always easy to do. Try to be specific about the things they could do to help.

#### **New friendships**

Don't be afraid to let those close to you know how you are feeling. Open communication with family and friends can sometimes lead to relationships becoming closer.

Having a child with a disability can also lead to new friendships and support networks.

## Siblings

# Brothers and sisters of a child with a disability face some unique challenges.

Sibling experiences and viewpoints are different from ours as parents.

A sibling's level of understanding of their brother or sister's disability will change as they grow and develop through childhood.

For example, it is common for a young child to think that they may have done something to cause their sibling's disability. As adults, it can be hard to imagine how a child could make such a connection.

#### Finding the right words

Finding the right words to explain a child's disability to another child can be difficult. Depending on the sibling's age and stage of development, consider their capacity to understand the issues and their ability to express themselves.

As children get older, they tend to ask more questions and seek more detailed explanations. Some questions may not have easy answers!

#### **Open communication**

Having good open communication can contribute significantly to a sibling's well-being.

Siblings need to know that you are available to answer questions about any aspect of their brother or sister's disability. They may also benefit from talking to an adult outside the family.

Siblings may find it helpful to connect with other siblings over the internet or in a sibling group, where they can share their thoughts, feelings and experiences.



"Life is different when you have a brother or sister with a disability because the experiences you go through in life, good or bad, are very different from those of other kids."

## Looking after yourself



"I used to feel guilty about this thing they called respite but I don't anymore. It gives me time to relax and recharge my energy levels. I look forward to it now as a positive thing for everybody."

# Looking after yourself can mean many different things.

With all the other demands and responsibilities in life, parents often tend to put themselves at the bottom of the list.

Amongst all the hospital visits, specialist appointments, therapy sessions and everything else you are involved with for your child, you also need to make sure that you don't forget to think about your own needs.

It could mean finding time to be with friends or your partner, spending some quality time with your other children, enjoying a hobby, or doing some voluntary or paid work.

#### Because you're worth it

Looking after yourself can sometimes seem like an impossible task and involve a lot of planning and organisation, but the benefits are worth it in the long run.

Taking regular time out for yourself is good for your own health and well-being.

By looking after yourself, you will be better able to look after your child and family.

## Your support network

#### As parents, we all need support.

In addition to professionals and services, it is important to think about other types of support that might benefit you and your family — your own personal and family support network.

Three ingredients for a strong support network are:

#### **Information**

Having, or knowing how to access, good information.

#### **Support**

Meeting other parents and sharing knowledge and experiences.

#### **Advocacy**

Belonging to groups that advocate for improvements to the service system.

When you combine all three, you have a powerful information and support network.

In addition to our Association, there is a range of disability-specific support groups and local, regional and state information and advocacy groups.

Explore what these groups have to offer and find out how they might become part of your personal and family support network.



"My main support network is the parents at my child's school. The conversations we have in the car park are sometimes more helpful than anything else."

## Role of services



"It took me a long time to get used to the idea that it's okay to ask for help from services."

# It can be difficult to take the first step and ask for help.

By creating and funding services to assist our families, society has acknowledged that we deserve access to appropriate support.

You should never feel guilty about asking for assistance from support services. They are there to help you and your family.

Services designed specifically for children with a disability and their families are sometimes referred to as specialist disability services.

There is also a range of other services available to all families which are sometimes called 'mainstream', 'generic' or 'universal' services.

#### Find out what works for you and your family

Every family has different needs and priorities for the best way services can assist. The range of services available to your family should be flexible and able to be adapted to suit your particular circumstances.

It is reasonable to expect that service providers will work together with you to identify and deliver the support that is most important to you and your family.

#### Be creative

Sometimes you have to be creative when working with service providers to put together a package of different services to achieve the support your family needs.

There can be long waiting lists for some services, which can be very frustrating. But it is always better to know about a service, and be able to explore options for accessing it in the future, than to not know it's there.

## Working together

# Good professionals see themselves as working together with parents.

There are many professionals and service providers whose job it is to help your child and family. They will be able to draw on their own particular skills and experience but it is impossible for them to know everything.

It is important to trust your instincts as a parent and to have your say about what you believe is right for your child and family.

#### Listen

As parents, it is important to encourage good working partnerships with professionals. We need to respect their role and listen to their point of view.

#### Ask

We also need to be prepared to ask questions or seek further explanations when we don't understand or agree.

#### **Trust your instincts**

Sometimes situations can arise which require us to challenge a professional. This is not always easy to do, and some professionals do not react kindly to being challenged.

But if you feel uncomfortable about the advice given by a professional, you should trust your instincts and seek further information or a second opinion.

In many areas of your life as a parent, you will soon discover that you need to become very good at standing up for yourself and your child.

You need to make sure your voice is heard and understood by the people who are making decisions that affect you and your family.



"I've learnt that for my family to get what we need I have to speak up and question things, otherwise we never seem to get anywhere."

## The information maze



"At first, I was overwhelmed with all the information.
Gradually, I learnt to sift through it all and work out what was relevant and what wasn't."

#### The service system is complex and confusing.

Some services are fully funded and administered by the Victorian Government (state). Others are fully funded by the Australian Government (federal). Some receive a combination of state and federal funding.

Most local governments also provide services for families of children with a disability.

There are also community organisations that provide services with the support of government funding.

#### **Finding your way**

It can sometimes take a lot of time to find your way 'through the maze' to the information you need. Thankfully, this task is made easier with the help of services that specialise in providing information.

#### **Putting it all together**

As parents, we need to develop skills, and find the time and energy, to piece together the information most relevant to us and our family.

Often the best results are achieved by seeking information from a range of sources, rather than relying on one professional or service provider.

It takes time to explore all the options, but the effort is usually worth it.

## Through the maze

There are some key places to start when working your way through the maze of services and support.

#### **Maternal and Child Health Service**

Your Maternal and Child Health nurse can give you links to a range of services and support, including playgroups and parent groups.

#### **Centrelink**

Most families of children with a disability are eligible for a fortnightly payment from Centrelink called Carer Allowance (Child). Eligibility includes families on all income levels. Applications can be made before a diagnosis is confirmed.

#### **Early Childhood Intervention Services**

Early Childhood Intervention Services for families of children with a disability aged 0–6 include a range of non-government and government services.

#### Child care

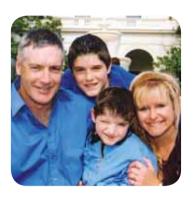
The Inclusion Support Program can provide support for children with a disability to attend child care.

#### **Kindergarten**

Kindergarten Inclusion Support Services and Preschool Field Officers can provide support for kindergartens to include children with a disability in kindergarten programs.

#### **Local government**

All local governments can provide access to a range of services and support for families of children with a disability, including the Home and Community Care (HACC) program.



"We were amazed to discover that our family was eligible for Carer Allowance (Child). It's not much, but that little bit extra it gives us a fortnight really helps."

## Children with autism



"The early intervention professionals offered guidance, support and practical solutions to everyday issues. They celebrated with me the beauty and joy of my child."

# Children with autism spectrum disorders can benefit from early support.

There is a range of support available for families of children with autism spectrum disorders (ASD).

#### **Getting a diagnosis**

If you think your child may have autism or an ASD, it's important to make an appointment with a professional as soon as possible. You can talk to your maternal and child health nurse, GP or paediatrician about getting a referral to a psychologist or psychiatrist who can assess your child. Even while you are waiting for a diagnosis you can begin finding out about services and support.

#### **Early intervention services**

There is a wide range of early intervention services and therapies available for children with ASD. Find out what these have to offer, including any cost, before you make a decision.

#### **Autism State Plan**

The Victorian Government has developed an Autism State Plan to build new and better approaches across government for meeting the growing and complex needs of people with ASD.

#### **Helping Children with Autism package**

Support available through the Australian Government's Helping Children with Autism package includes Autism Advisors, early intervention services, PlayConnect Playgroups, Autism Specific Early Learning and Care Centres, Early Days Workshops for parents, professional development for teachers and school staff, and an ASD website.

#### **Raising Children Network ASD website**

http://raisingchildren.net.au/children\_with\_ autism/children\_with\_autism\_landing.html

## Parent support

Sometimes it helps to talk things through with someone who understands things from a parent perspective.

Every child is unique and every family is different. No two situations are the same.

Many parents call our Parent Support Workers for information and support each year. Some inquiries have easy answers. Others involve complex issues that may need many conversations and follow-up over a number of weeks.

You might have all the right information but need help understanding what it means for you and your family.

Our Parent Support Workers can:

- Listen to the issues you need help with.
- Give you information about services and support available to you and your family.
- Help you develop skills in what we call 'parent advocacy' and learn how to negotiate and advocate on behalf of your child and family.

All of our Parent Support Workers are parents of children with a disability.

In helping you and your family, our Parent Support Workers draw on their own experiences and those of the many other parents who have been involved with our Association over the years.

Please remember that you can ring and speak to our Parent Support Workers about any disability issue.



"The Parent Support
Worker was great.
She listened while I
talked, and talked, and
talked some more! We
sorted through some
of the practical things
I needed help with and
I got off the phone
feeling much better."

## Parent advocacy



"I made sure I had a clear plan of what we needed. They seemed to listen more after that."

Being an effective advocate is one way to work towards getting the best for your child and family.

It isn't easy being an advocate for your child. Sometimes emotions take over.

Advocacy can also be exhausting!

But with persistence and the right support, parent advocacy can help you get what you and your family need.

To be an effective advocate:

- Be clear about what you want.
- Find out who is responsible or accountable for the decision and action you seek.
- Listen to other people's points of view.
- Think about the points that others may raise and how you might respond.
- Don't always expect conflict but be prepared with a positive strategy if you do strike conflict.
- Be open-minded, others might suggest solutions that you may not have thought of or different ways of doing things that may be just as effective.
- Draw on strong emotion if you need to.
- Ask a friend or professional to help you with advocacy if you need some support.

## **Key Contacts**

## Action on Disability within Ethnic Communities

Phone: 9480 1666 Web: www.adec.org.au

#### **Association for Children with a Disability**

Phone: 03 9818 2000 or 1800 654 013 (rural callers) Web: www.acd.org.au

#### **Australian Physiotherapy Association**

Phone: 1300 306 622

Web: www.physiotherapy.asn.au

#### **Better Health Channel**

Web: www.betterhealth.vic.gov.au

#### **Better Start**

Phone: 1800 778 581 - Helpline Web: www.fahcsia.gov.au

#### **Carers Victoria**

Phone: 1800 242 636 Web: carersvictoria.org.au

#### **Catholic Education Office**

Phone: 9267 0228

Web: www.ceomelb.catholic.edu.au

#### Centrelink

Phone: 13 27 17 (Carer Allowance/Payment) Phone: 13 61 50 (Family Payments, Child Care)

Phone: 13 12 02 (Languages) Web: www.humanservices.gov.au

## Child and Adolescent Mental Health Services (CAMHS)

Web: www.health.vic.gov.au/ mentalhealth/services/child

#### **Community Child Care**

Phone: 9486 3455 Web: www.cccinc.org.au

#### **Child Care Access Hotline**

Phone: 1800 670 305

#### **Commonwealth Respite and Carelink Centre**

Phone: 1800 052 222

Web: www9.helath.gov.au/ccsd/index.cfm

## Department of Education and Early Childhood Development (DEECD)

Web: www.education.vic.gov.au

## DEECD Regional Offices Early Childhood Intervention Services Central Intake

Web: www.education.vic.gov.au/ ecsmanagement/intervention

#### **Eastern Metropolitan Region**

Phone: 1300 662 655

#### **Northern Metropolitan Region**

Phone: 9304 0775

#### **Southern Metropolitan Region**

Phone: 1300 720 151

#### **Western Metropolitan Region**

Phone: 9275 7500

#### **Barwon South Western Region**

Phone: 1800 354 605

#### **Gippsland Region**

Phone: 1800 33 60 10

#### **Grampians Region**

Phone: 5330 8608 or 5330 8613

#### **Hume Region**

Phone: 1800 627 391

#### Loddon-Mallee Region

Phone: 1300 363 514

#### Department of Families, Housing, Community Services & Indigenous Affairs

(FaHCSIA)

Phone: 1300 653 227 Web: www.fahcsia.gov.au

## **Key Contacts**

## **Department of Human Services Disability Services Division**

#### **Disability Intake and Response**

Phone: 1800 783 783 Web: www.dhs.vic.gov.au/ for-individuals/disability

#### **Disability Services Commissioner**

Phone: 1800 677 342 Web: www.odsc.vic.gov.au

#### **Divine**

Web: www.disability.vic.gov.au

## **Early Childhood Intervention Australia** (Victorian Chapter)

Phone: 9819 5266 Web: www.eciavic.org.au

#### **Family Assistance Office**

Phone: 13 61 50

Web: www.humanservices.gov.au

#### **Families Australia**

Phone: 02 6273 4885

Web: www.familiesaustralia.org.au

#### **Family Relationships Online**

Phone: 1800 050 321 – Advice Line Web: www.familyrelationships.gov.au

#### **FKA Multicultural Resource Centre**

Phone: 9428 4471 Web: www.fka.com.au

#### **Genetic Support Network Victoria**

Phone: 8341 6315 Web: www.gsnv.org.au

#### **Independent Schools Victoria**

Phone: 9825 7200

Web: www.independentschools.vic.edu.au

#### **Infoxchange Australia**

Web: www.infoxchange.net.au

#### **Kids Help Line**

Phone: 1800 551 800 Web: www.kidshelp.com.au

#### **Kids Connect (Find a doctor)**

Web: www.rch.org.au/kidsconnect

#### **Kindergarten Parents Victoria**

Phone: 9489 3500 Web: www.kpv.org.au

#### Lifeline

Phone: 13 11 14

Web: www.lifeline.org.au

#### **Maternal and Child Health Line**

Phone: 13 22 29

Web: www.education.vic.gov.au

#### **Medicare**

Phone: 13 20 11

Web: www.humanservices.gov.au

#### **Mensline Australia**

Phone: 1300 789 978 Web: www.mensline.org.au

#### **Municipal Association of Victoria**

Phone: 9667 5555 Web: www.mav.asn.au

#### **My Time Support Groups**

Phone: 1800 889 997 Web: www.mytime.net.au

#### **National Continence Helpline**

Phone: 1800 330 066

Web: www.continence.org.au

#### **National Relay Service**

Phone: 1300 555 727 (Voice) or 133 677 (TTY)

Web: www.relayservice.com.au

#### **NICAN - Recreation and the arts**

Phone: 1800 806 769 Web: www.nican.com.au

#### **Noah's Ark Inc**

Phone: 8823 8600

Web: www.noahsarkinc.org.au

#### **NURSE-ON-CALL**

Phone: 1300 606 024

Web: www.health.vic.gov.au/nurseoncall/

## **Key Contacts**

#### **OT Australia Victoria**

Phone: 9481 6866

Web: www.otaus.com.au/divisions/vic

#### Office for Disability

Phone: 9096 0574

Web: www.dhs.vic.gov.au

#### **Parenting Research Centre**

Phone: 8660 3500

Web: www.parentingrc.org.au

#### **Parent Line**

Phone: 1300 301 300

Web: www.parentline.com.au

#### **Playgroup Victoria**

Phone: 1800 171 882

Web: www.playgroup.org.au

#### **Program for Students with Disabilities**

Web: www.education.vic.gov.au

#### **Raising Children Network**

Web: www.raisingchildren.net.au

#### **Relationships Australia**

Phone: 1300 364 277

Web: www.relationships.org.au

#### **Royal Children's Hospital**

Phone: 03 9345 5522 Web: www.rch.org.au

#### Speech Pathology Australia

Phone: 1300 368 835

Web: www.speechpathologyaustralia.org.au

#### **Translating and Interpreting Service**

Phone: 13 14 50

Web: www.immi.gov.au/living-in-australia/ help-with-english/help\_with\_translating

## Victorian Aboriginal Education Association

Phone: 9481 0800 Web: www.vaeai.org.au

#### **Victorian Aboriginal Health Service**

Phone: 9419 3000 Web: www.vahs.org.au

## Victorian Co-operative on Children's Services for Ethnic Groups (VICSEG)

Phone: 9383 2533

Web: www.vicseg.com.au

#### **WIRE - Women's Information**

Phone: 1300 134 130 Web: www.wire.org.au

## Additional support for families of children with ASD

#### **Amaze (formerly Autism Victoria)**

Phone: 1300 308 699 Web: www.amaze.org.au

#### **Early Days Workshops**

Phone: 1300 307 909

Web: www.raisingchildren.net.au/ articles/early\_days\_autism\_

workshops.html

## Helping Children with Autism ASD Support Helpdesk

Phone: 1800 778 581 Web: www.fahcsia.gov.au children\_with\_autism/children\_

#### **PlayConnect Playgroups**

Phone: 1800 790 335

Web: www.playgroupaustralia.com.au

## Raising Children Network ASD website

Web: http://raisingchildren.net.au/

with autism landing.html

#### **Autism Help**

Phone: 5221 2984

Web: www.autismhelp.info

## Notes

## **Parent feedback**

Your feedback will help us provide information that is relevant and of interest to families of children with a disability. After completing the survey please tear off this page and post to **Association for Children with a Disability, Reply Paid 84584, Hawthorn VIC 3122.** You can also email feedback to **mail@acd.org.au** or fax it to **03 9818 2300**.

Did the <b>Helping You and Your Family</b> booklet provide you with the information you were looking for?	Yes	No
What other information would you like to see included?		
Was the information easy to find?	Yes	No
Could the layout or design be improved to make it easier to read?	Yes	No
Could the layout or design be improved to make it easier to read?  If yes, how?	Yes	No
If yes, how?		

Any other comments?
Thank-you

#### Membership

If you're not already a member of our Association you might like to consider joining.

#### Membership is FREE for families for the first 12 months.

Benefits of membership include our member magazine, NoticeBoard, which includes family stories, news and information about services and changes to government policy.

We encourage families to join our Association as well as other disability self-help groups. Our aim is to work together on issues that reach across all disabilities.

Service providers, organisations, interested persons and other community supporters are also encouraged to join our Association.

In addition to membership, we also welcome donations. All donations over \$2 are tax deductible.

For more information contact the Association office on **03 9818 2000 or 1800 654 013 (rural callers)**, by email **mail@acd.org.au** or visit **www.acd.org.au** 





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