



Resource Guide for Families Caring for Medically Complex Children

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Does your child require complex care?

If you answered yes to most of the questions listed below, your child is medically complex.

1



Does your child see multiple medical specialists, attend multiple therapies, and require educational accommodations?

2



Does your child have one or more serious chronic medical condition that places them at a higher risk of going to the hospital?

3



Does your child depend on life-sustaining technology to survive? (e.g. feeding tube, breathing tube, oxygen, nebulizer)

4



Is caring for your child's health causing significant burn out with frequent provider visits and financial burden?

Know your coverage!

Specific to California Residents



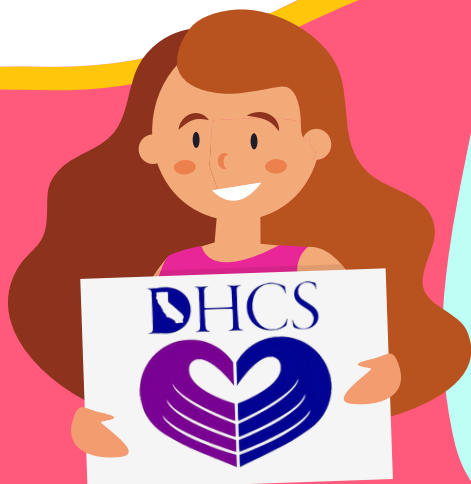
Don't Qualify for Medi-Cal?

If your family doesn't qualify for Medi-Cal or uses a different insurance, your child may still qualify for Medi-Cal under their name for any services related to their medically complex condition!



California Children's Services (CCS)*

Helps provide coverage in addition to your child's current insurance plan for services related to specific medical conditions.



Covers medical and therapy services for children who:

- Have a CCS eligible medical condition (most medically complex children qualify)
- Are under 21 years old
- Are residents of California
- Are financially eligible based on family income

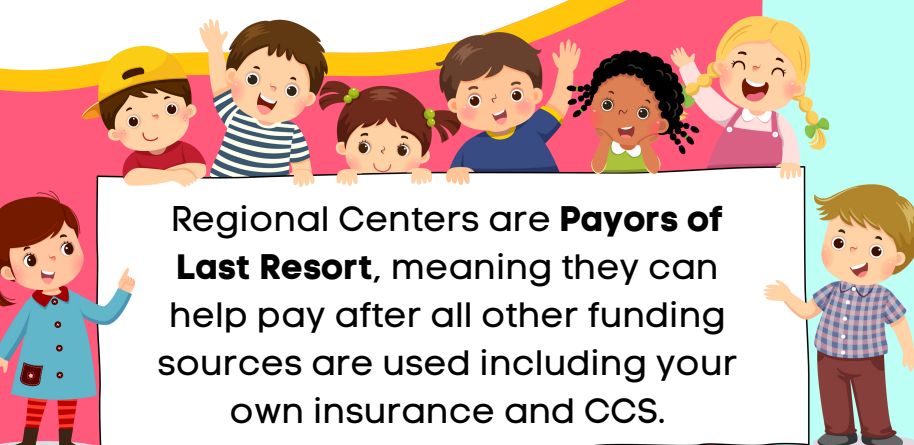
Regional Centers**

There are 21 Regional Centers throughout California, private non-profit organizations under contract with California Department of Developmental Services who help support children with **developmental disabilities**.

Types of Services provided may depend on county.

Examples include:

- Respite Care
- Early intervention services for infants between birth to 3 years
- Diagnostic evaluations to establish eligibility
- Case Management
- Service Coordination

A cartoon illustration of a group of six diverse children (three boys and three girls) and two adults (a girl on the left and a boy on the right) holding a large white sign. The sign contains text about Regional Centers being payors of last resort.

Regional Centers are **Payors of Last Resort**, meaning they can help pay after all other funding sources are used including your own insurance and CCS.

For more information:

*<https://www.dhcs.ca.gov/services/ccs/Pages/default.aspx>

**<https://www.dds.ca.gov/rc/>

What services may your child need?

Safety/Adaptive Equipment:

Many medically complex children use assistive devices to help with activities of daily living. Making sure your child has proper adaptive equipment can keep you and your child safe!

Examples include: Manual vs electric wheel chair, car seat, bathing chair, specialized toilet seats, safety bars, activity chairs, transfer lifts for car or stairs.



Physical Therapy/Occupational Therapy:

Aims to improve physical functioning in children with special needs to maximize independence and performance of day to day tasks while staying safe.



Education Services:

If your child has any challenges that impact learning such as developmental delays or use of life-sustaining technology, you may be eligible to enroll in special education services. This will provide access to aides and school nursing support while at school.

Early Start Services (birth-3): Early intervention services set up by your local regional center can significantly improve your child's future development!

IEP (PreK-12): Based on your child's specific needs, you can work with a public school to create an **I**ndividualized **E**ducation **P**rogram with specialized instructions, accommodations and services to best help your child learn.

504 Plan (PreK-12 and beyond): If your child does not qualify for an IEP, you can still apply for a 504 plan. While it does not provide specialized instructions, it allows for accommodations to ensure academic success.



Services Continued...



Speech Therapy:

Therapists work with your child on language and fluency to improve communication. This is typically accessed through your child's school.

They also help with any feeding or swallowing issues with your child. Children who need speech therapy should start earlier rather than later!

Transportation:

If your child has an IEP, they may be entitled to special needs transportation to and from school if deemed necessary.

Transportation to and from your medical appointments may be covered by your insurance, Medi-Cal, or CCS.



Special Needs Dentist:

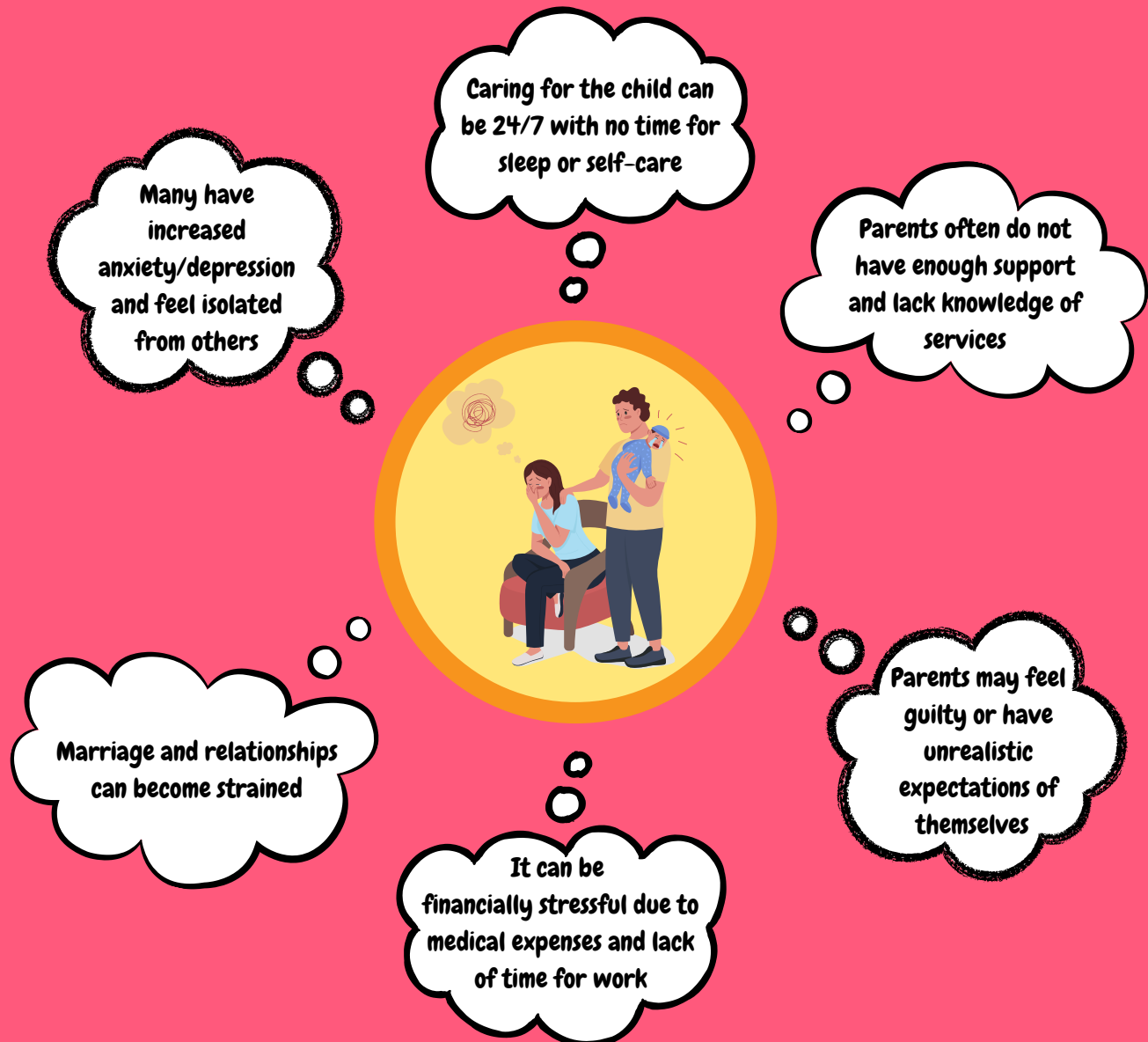
Special needs dentists are trained to take care of kids with developmental or physical disabilities.

They are able to provide general anesthesia during procedures which many medically complex children require.

Their practices may also have specialized equipment to accommodate any of your child's needs.

What is Caregiver Burden?

Are you feeling burned out? If so, you are not alone! Caregivers of medically complex children with intense needs have substantial responsibilities that can lead to overwhelming mental and physical exhaustion.



If you are feeling burned out, know that there are resources and support groups available to help!

Help is Available!

Need a break? Here are some resources that can help!

Respite Care

Trained respite care providers can provide you with a much needed break to destress, reenergize, and take care of errands. It can be arranged for just a few hours a week or several days. Respite care can take place in your own home, day care centers, or health care facilities. While it does cost money, waivers are available!



Medically Fragile Daycare

This is for medically complex children that require special attention or equipment not found in regular daycares. Staff may consist of nurses and specialists who will work to match the clinical requirements while providing an enriching education. Ask your primary care provider to see if there are any in your area.



In Home Supportive Services (IHSS)

Caring for a medically complex child can be demanding. Many caregivers are not able to work because of the time spent taking care of their child. For these caregivers, there is a program called IHSS which can help. This program compensates caregivers for the medical care they are providing for their child (treatments, medications, tube feeding, suctioning, etc.)






Palliative & Hospice Care For Your Child

What is Pediatric Palliative Care?

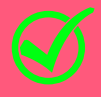
It is specialized family-centered care aimed at maximizing comfort, relieving symptoms, and providing extra support while continuing life-prolonging treatment.

Your child may greatly benefit from palliative care if they have a serious illness, ongoing disease or disability impacting their quality of life. **Many families who qualify for palliative care wish they started using it earlier!**

Fiction

-  Only for people who are dying
-  Only used for pain
-  Abandonment of treatment
-  Only available in hospitals
-  Costs a lot of money out of pocket

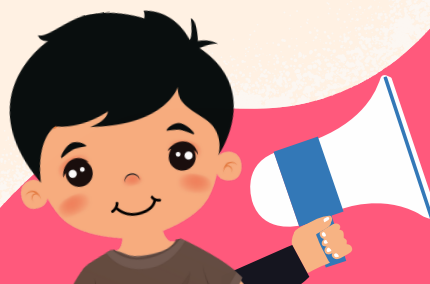
Fact

-  Palliative care can be at any stage of an illness. Does not have to be terminal.
-  It provides more than just physical care, but also emotional and spiritual support.
-  Curative or life-prolonging treatment will continue to be given.
-  It can be at home, hospital, long-term care facility, or rehab center.
-  Visits are often covered by Medical and most commercial insurers

What is Hospice Care?

Hospice care also provides compassionate comfort care, but is limited to children with less than 6 months to live due to a terminal illness. A specialized team of experts work closely with the family to provide support and care with the goal of improving quality of life.

This can be done in the comfort of the child's home, a care facility, or hospital.



Palliative Care is **NOT the same as Hospice Care**

Experiencing financial strain? You may qualify for free or reduced cost services.

If applicable, your insurance, CCS or Medi-Cal may cover medical equipment and supplies that are deemed necessary for your child!



Incontinence Supplies: Diapers and wipes for children over 5 years old



Specialized Infant Formula that is medically necessary



Aids such as power/manual wheelchairs or crutches



Feeding tubes, syringes, oxygen, etc.

Other Resources your family may need!



For more resources, go to your primary care provider for SDH/ACEs screening! Your doctor can use these screening tools to assess your needs and provide further resources and referrals.

Utilities

There are discount programs available to help reduce the cost of your utilities bill.

Eligibility is based on income and household number.

Power Dependence

For those who depend on electrical medical devices to survive, some programs may offer extra notifications for public safety power shutoffs and portable backup batteries.

DMV Placard

If you're a primary caretaker of a child with significant developmental or physical disabilities, you may qualify for a handicapped placard.

Social Determinants of Health (SDH) Screening:

SDH screening can be done with any member of your care team! It allows your doctor to better understand what social and environmental factors may be preventing you and your child from achieving a healthy lifestyle!

SDH

Housing instability
Food insecurity
Transportation Issues
Financial Strains/Utilities
Safety
Employment
Community Support
Education Needs
Disabilities
Mental Health

Your care team may be able to offer you resources or connect you with someone who can help!

For example:

If you don't have enough money to buy healthy food options, you might be recommended programs like **CalFresh** and **WIC** that can help!



Adverse Childhood Experiences (ACEs) Screening:

ACE screening can be done with any member of your care team! It aims to identify harmful childhood experiences that can increase the risk of unhealthy behaviors, chronic diseases and toxic stress as an adult.

1

Abuse

2

Neglect

3

Household dysfunction



*

Negative Health Outcomes

*



Risky behaviors (Drugs/Alcohol)



Chronic Diseases (Diabetes, Obesity)



Mental Illness (Depression)



Education/Employment Struggles

Prevention and interventions such as mental health/behavioral support can reduce harm and increase resilience in children!

Know your ACE score!

Who to Contact for More Information



1. Your primary care provider



2. Your social worker/case manager



3. CCS worker



4. Regional Center worker



5. Regional Public Health Department



6. School Nurse



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