



Caring for Special Needs Patients

*A systematic approach to assessments,
communication, and treatment.*

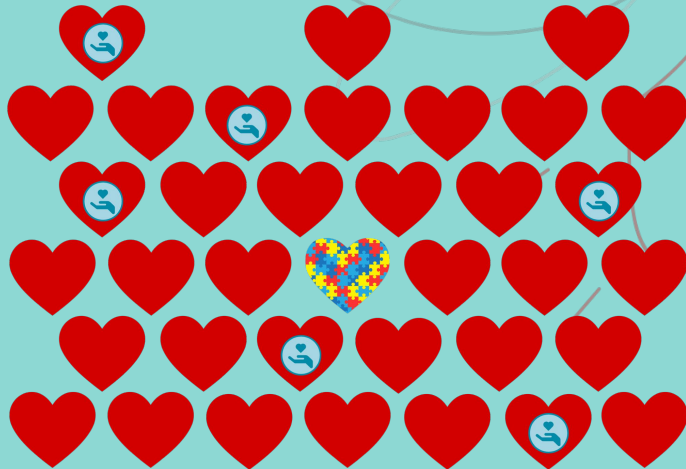


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Updated: January 2025

Special needs children in our communities.

According to the U.S. Centers for Disease Control (CDC) 2020 analysis of all Autism and Developmental Disabilities Monitoring Networks (11 in total nation wide) “about 1 in 36 children has been identified with autism spectrum disorder (ASD)”.

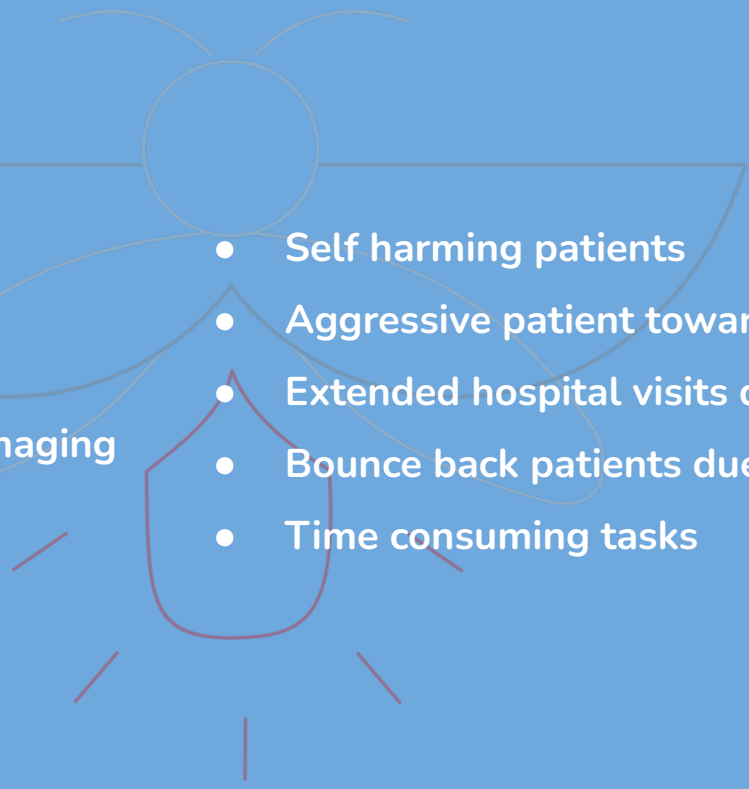


“About 1 in 6 (17%) children aged 3-17 years were diagnosed with a developmental disability... including autism, attention-deficit/hyperactivity, disorder, blindness, and cerebral palsy, among others.”

CHALLENGES FOR HEALTHCARE WORKERS



- Delays in care
- Frustrated family
- Difficult med passes
- Movement during exams/imaging
- Communication barriers
- Self harming patients
- Aggressive patient toward staff
- Extended hospital visits due to inefficient care
- Bounce back patients due to ineffective care
- Time consuming tasks



Delays in care.

Understanding your special needs population can be difficult at times and the lack of specialized education, tools, and approaches to this population often creates delays in care for those children.



“When a crisis occurs and children with special health care needs must access the emergency system, they are often left vulnerable because of the lack of access to information about their medical problems. There can be delays in treatment, unnecessary tests, and sometimes serious errors as a result of lack of access to information available”. (2)

Family Centered Care

No parent wants to see their child sick or injured.

When a child comes to the emergency department or is admitted to the hospital the whole family's experience should be taken into consideration.

The parents are your #1 resource.

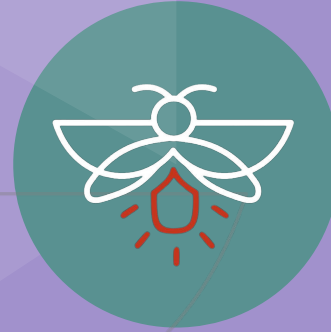
No one will know their children more than their parents so including them into the assessment and plan of care is invaluable. They know their special needs child's baseline, communication, and sensory needs better than anyone.



THREE KEY FACTORS TO TAKE INTO CONSIDERATION.

#1: COMMUNICATION NEEDS

A big challenge is communication with special needs children of all ages. Their biological age may not correlate with their communication level. Special needs children's communication needs may be a mixture of more than one form.



Some of the communication needs to take into consideration are:

- Verbal
- Nonverbal
- Pictures
- Drawings
- Mimicking/Echolalia
 - Sounds
 - Objects
- Timelines
- Providing options
- Consistency with staff
- Using short phrases
- Repetitive words/movements

THE IMPORTANCE OF SENSORY-FRIENDLY ENVIRONMENTS

REDUCED ANXIETY

Spaces that avoid overstimulation can lessen feelings of anxiety.



IMPROVED COMFORT

Calming surroundings promote a greater sense of physical and emotional ease.



ENHANCED FOCUS AND ENGAGEMENT

By minimizing distractions, sensory-friendly spaces allow for better concentration on tasks.



INCREASED SELF-REGULATION

Access to tools that support self-soothing enables individuals to manage their sensory experiences more effectively.



THREE KEY FACTORS TO TAKE INTO CONSIDERATION.

#2: SENSORY NEEDS

When a special needs child is in need of medical attention it is important to remember that taking a moment to understand sensory triggers will not only make the patient more comfortable but will build a sense of trust in you that will make carrying out your tasks more efficient.

Consideration should be given to sensory needs, which may include seeking or avoiding/sensitivity to:

- Room lighting
- Reduction of noise
- Colors
- Physical touch
- Textures
- Temperature
- Taste
- Smells

THREE KEY FACTORS TO TAKE INTO CONSIDERATION.

#3: SUPPORTS

When caring for a patient with special needs, it is essential to identify and implement additional support measures to ensure their safety, follow best practices, enhance comfort, and facilitate the medical practitioner's ability to perform their job effectively. Supportive measures should be implemented based on the patient's *specific needs* to create a sensory-friendly and comfortable hospital experience such as:

- Providing tools related to sensory concerns (i.e. patient is sensitive to sound, benefits from wearing noise canceling headphones)
- Rewards system
- Visual supports (i.e. pain scale, schedule)
- Door/entry notice of aggressive behaviors
- Behavioral support (i.e. “first, then” visual - “first we draw your blood, then you can use the fidget”)





FIREFLY

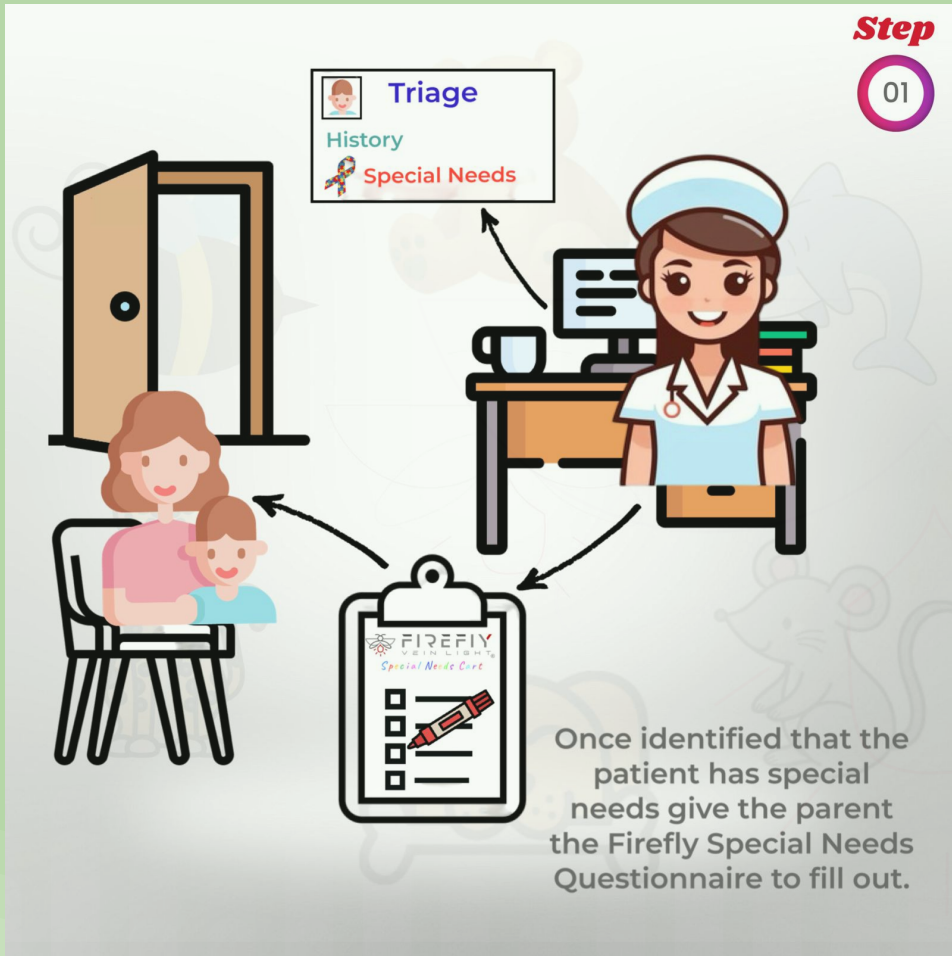
VEIN LIGHT®

Special Needs Cart

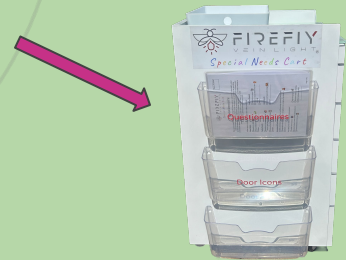


BRINGING IT ALL TOGETHER!

A STEP BY STEP SYSTEMATIC APPROACH.



The Firefly Special Needs Cart starts at the very first interaction when the nurse identifies the patient has special needs with the **Firefly Special Needs Questionnaire** (located on the left side of the **Firefly Special Needs Cart**).



Once check in to the hospital, if there is not a life threatening emergency, the triage nurse should ask the parents to complete the questionnaire and provide it to their assigned nurse.

Each answer has a unique icon beside it.

Questionnaire

This special needs questionnaire is designed to help us better understand your child's unique needs and experiences as they prepare to visit the hospital or care facility. By providing detailed information about your child's abilities and needs, your insights are invaluable in helping us provide the most appropriate and comfortable care to your child and your family. There are checkboxes and text boxes that apply to your child.

What sensory concerns your child has? (check all that apply)

Visual/Sight:

- Sensitive to light
- Vision
- Other: _____

Tactile (Touch):

- Sensitive to touch (touch from others, tapes, band aids, etc.)
- Textures
- Other: _____

Movement & Position:

- Seeks movement as a stimulation
- Responds well to deep pressure (weighted vest, weighted lap buddy)
- Other: _____

How does your child primarily communicate?

- Verbal communicator
- Limited verbal communicator
- Communication device user

Auditory (Sound):

- Sensitive to sounds
- Musicals
- Calming
- Other: _____

Oral (Mouth):

- Seeks oral input (chewing)
- Other: _____

Page 1 of 2

Cuestionario

Este cuestionario especial está diseñado para ayudarnos a comprender mejor las necesidades especiales y experiencias mientras se prepara para visitar el hospital o el centro de atención. Al proporcionar información detallada sobre su hijo a través de esta encuesta, sus conocimientos son invaluable para ayudarnos a brindar el cuidado más apropiado y cómodo para su hijo y su familia. Hay casillas de verificación y espacios de texto que se aplican a su hijo.

¿Qué necesidades especiales tiene su hijo? (marque todas las que correspondan)

Auditivos (Sonidos):

- Sensible al sonido
- La música
- El sonido son calmante
- Otros: _____

Oral (Boca):

- Busca entrada oral (chewing)
- Otros: _____

Comunicación:

- Comunicador verbal
- Comunicador verbal limitado
- Usuario de dispositivo de comunicación

Page 1 of 2

Step

02

The parents will know their child more than any medical staff will and the *Firefly Special Needs Questionnaire* allows them to play an active role in the care of their child.

The (2 sided) reusable *Firefly Special Needs Questionnaire* cover the most common **communication, sensory, and support needs** for children with special needs diagnosis.

Each answer has a unique icon associated with the *Firefly Special Needs Cart*.

Comes in English & Spanish.

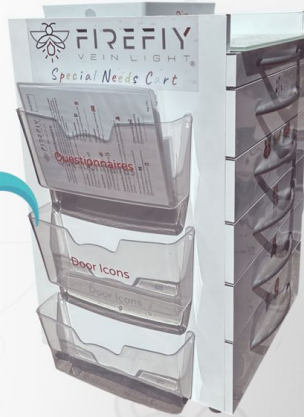
(other languages available upon request)

Icon Book

20 Different Icons

Step

03



Front



Back

The unique icon associated with the answers from the Firefly Special Needs Questionnaire can be found in the binder on the side of the Firefly Special Needs Cart.

The nurse or other ancillary staff are to pull the appropriate unique icons from the binder (one of each up to four max. Preferably one from each color if applicable).

At this point the reusable can be placed in the dirty bin on top of the cart to be wiped clean.





Door Display

Step

04

Place appropriate icons on the patient's door to inform the care team of the child's needs.



The nurse or ancillary staff will then place the appropriate (4 max) **unique icons** on the provided hanging door icon holder on the patient's assigned room. If the assigned bed or exam area does not have a door (curtain or divider) place icon holder where visible to care team.

The icon side should be facing outward and the text side should be facing the door (rational explained on the next slide).

Interpreting the Icons

Step

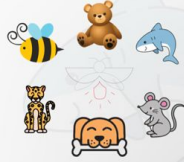
05

Only the icon faces forward to ensure patient privacy and integrity.



The back of each card describes the patient's needs.

19 Icons



4 Colors

Coordinated Categories

Communication

Sensitivity

Caution

Calming

&



Badge buddies have the description of each icon.

Each **unique icon** has been hand designed by TEAM FIREFLY in a systematic way that makes interpretation fast and effective.

There are 19 different icons that each represent a tool(s) in the Firefly Special Needs Cart (elaboration on next slide) or in the event of the yellow "caution" category, give the provider a warning of potential high risk patients.

Each of the 4 colors has identified a different category.

The explanation of each icon is on the door facing side of the icon cards as well as on the provided badge buddies (25 per cart purchase included).



FIREFLY
VEIN LIGHT®

Step

06

Special Needs Cart



Used Items

> 50 Communication/Sensory
Items Included



Icon guided
drawer labels.



Each drawer on the Firefly Special Needs Cart is labeled with the unique icons from the parents answers to the *Firefly Special Needs Questionnaire*.

The Firefly Special Needs Cart contains over 50 communication, sensory, and support tools that integrates outpatient pediatric occupational therapy concepts and bedside pediatric nursing application.

The icon based system make providing the correct tools fast and effective.

***Sensory tools to calm & distract
(or engage) patients during
medical interventions.***

Step

07

Goals:

***Meet the patient's
communication needs.***

***Distraction tools that best
captures the patient's
attention.***

***Execution of care with
decreased resistance and
delays.***

***Increase in patient and
family satisfaction
scores.***

Our goal at Firefly is help medical staff understand the unique communication, sensory and support needs of the special needs population in order to:

- Reduce delays in care.
- Reduce traumatic experiences for the patient by provided comfort and calming measures.
- Have greater success at first attempt interventions.
- Reduce bounce back patients and extended hospital stays.
- Increase staff confidence with special needs patients.
- Increase patient and family satisfaction.

After Use of Items.

Step

08

**Dirty bin for tools that
need to be wiped clean.**

Item return/restock:

**Chart on the side of the
cart with which drawer
the items belong in.**

**Each item has a QR code for
reordering in the event a tool
is accidentally misplaced or
taken by the patient.**

All items reusable.

(Recommended single use for oral chewies)



There is a fixed dirty tool bin mounted on the top of the Firefly Special Needs Cart so that the used tools do not get displaced after use if they cannot be immediately wiped clean and returned to their designated drawers.

On the right side of the cart there is a guideline (with images) to which drawer each tool is to be returned to.

In the event that a tool goes missing (accidentally taken to the floor or taken by a family member) and cannot be tracked or recovered the list on the side has QR codes linked to where to reorder the missing item(s).

COMMUNICATION

Identify the patient's preferred form of communication based on the parent's responses in the questionnaire, and provide tailored communication support to encourage positive interactions, foster cooperation, and improve self-regulation.

EXAMPLE:

“My child uses an AAC device iPad to communicate and as a family, we use a visual schedule to set the expectation”



SENSORY

About 90% of Autism Spectrum Disorder individuals have atypical sensory experiences, described as both hyper- and hypo-reactivity, with abnormal responses to tactile stimulation representing a very frequent finding. (5)

Identify the sensory need, per questionnaire results, whether it is that a patient seeks out, avoids and or is sensitive to certain inputs and adjust the treatment plan to provide extra support.

EXAMPLE:

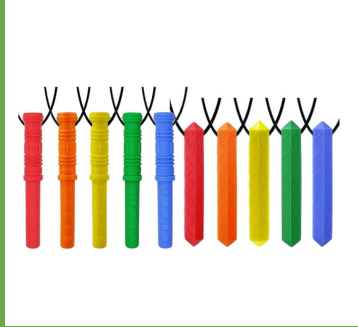
“My child is hyper-sensitive to noise and uses noise-cancelling headphones, but we didn't bring ours. My child also loves deep pressure & weighted items.” -Mom

ED staff provides noise cancelling headphones and a weighted lap buddy to meet sensory needs.



WHAT DOES THE SCORE MEAN?


EXAMPLE 1:



Special Needs Questionnaire

Result:

Oral (Mouth):

- Seeks oral input (chewing) 
- Other: Chews on everything



Sensory drawer labeled 

Retrieve disposable chewy from sensory drawer to bring to patient.

Chewy's -Providing an oral stimulation chewy tool can help meet the child's sensory needs, promoting regulation during a medical visit.



WHAT DOES THE SCORE MEAN?


EXAMPLE 2:



Special Needs Questionnaire

Result:



Movement & Body Position

- Seeks movement as a regulation tool (bouncing, spinning, pacing, etc.)
- Responds well to deep pressure (weighted vest, weighted lap buddy) 
- Other: _____

What communication supports work best for your child?

- Visual schedule 
- "First... then..." Language or visual 
- Choice board 
- Written instructions 
- Other (please specify): _____



1. Sensory drawer labeled 
2. Communication support drawer labeled 

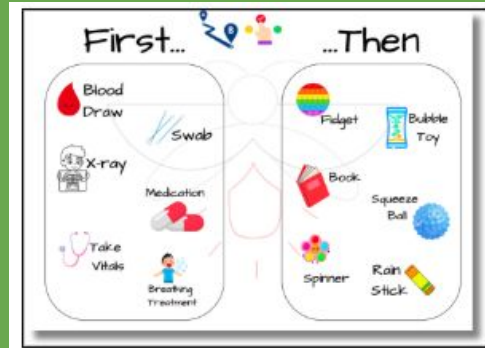
1. Retrieve weighted lap buddy from sensory drawer to bring to patient.

Weighted lap buddy - Providing proprioceptive input through deep pressure as a calming and regulation strategy.

2. Retrieve "First, then" visual with white board marker to create supportive communication tool to help reduce anxiety, improve cooperation and provides clear structure.



EXAMPLE 3:



SUCCESS STORY

7yo male with history of autism disorder (nonverbal) and asthma is brought in to the emergence department by his mother for respiratory distress. The patient moderate work of breathing with wheezing on auscultation. Patient fighting the monitor and assessment.

Treatment: PO steroids and a 1 hour continuous breathing treatment.

The RN used the special needs questionnaire with the mother and identified that the patient has a tactile sensitivities to a variety of textures but finds soft fabrics are a calming sensation for the child. The patient is nonverbal but the questionnaire identified that the patient will point and mimic sounds to communicate. As a reward the mother provides picture books to reinforce positive behavior.

With this information the RN went to the special needs cart and found a farm animals picture book that had a variety of soft fabrics that imitate the animals fur. The RN presented this to the patient and instantly the stopped fighting the monitor and the staff and could not stop pointing to the animals, imitating their sounds and petting the fur in the book.

The patient took his PO medications and stayed calm for the duration of the 1 hour long breathing treatment.

The mother was in tears because she had never had staff take the time to understand her child in the ED in this way before. The patient was successful treated and discharged within two hours.



References

- (1): [Data and Statistics on Autism Spectrum Disorder | Autism Spectrum Disorder \(ASD\) | CDC](#)
- (2): [Emergency Preparedness for Children with Special Health Care Needs](#)
- (3): [How to Build Sensory-Friendly Environments for Autistic People - Rainbow Therapy](#)
- (4): [Autistic children & communication skills | Raising Children Network](#)
- (5): [Sensory Abnormalities in Autism Spectrum Disorders: A Focus on the Tactile Domain, From Genetic Mouse Models to the Clinic](#)