

# Layla Al-Badri Loucopoulos

## Parents' Report

20 April 2023



Our driving question in all things is:  
**How do we enable Layla's voice and her quality of life?**

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## Gratitude

**Our family is deeply grateful to Layla's team of heroes that are giving her the quality of life that all souls deserve.**

**We are in your debt for giving so much care and love to our beautiful and perfect daughter, and by extension, all of our family.**

**Thank you from our hearts.**

**Dad 1**

**Mr Costa Loucopoulos**

**Dad 2**

**Dr Ghaith Al-Badri**



## About Layla



Layla was born on 18 September 2022 and is now seven months old.

She lives with her two dads, Ghaith and Costa, as well as her sister Pan and Yiayia Yiota.





Layla loves playing with her sister on a sunny day more than anything else.



Layla loves water and play. She likes to be included in games and to see people smiling (she will mirror your expression).



Layla's favourite book at the moment is Baby Penguin



She responds well to puppets and inanimate objects that are in her proportions and with large expressive eyes. She reacts with verbal and physical expressions of joy to Cindy, the puppet, in particular.









# Layla's Early Learning & Play Experiences Program

## Early Learning and Play Experiences

Layla Al-Badri Loucopoulos

Educator: Sue Orlovich

Developmental Area	Date: 14.4.23	Date: 20.4.23	Date: 24.4.23	Date: 25.4.23
	<b>Session Focus:</b> Introduction to Sue and Cindy (with Costa)	<b>Session Focus:</b> Bath time	<b>Session Focus:</b> Greetings/Nursery rhymes/ actions	<b>Session Focus:</b> Greetings/Nursery rhymes/ actions
<b>Physical</b>	<b>Focus:</b> Stroking of arm, touching of nose.	<b>Focus:</b> Water sensory play- splashing, kicking, floating, warmth	<b>Focus:</b> Upright positioning and head/neck support Touching, holding and grasping	<b>Focus:</b> Upright positioning and head/neck support Touching, holding and grasping
<b>Noticing/notes:</b>	14.4. Layla enjoys having Cindy stroke her arm and she moves her arm when Cindy touches her hand. 20.4 Layla loved puppets at bath time and smiled as warm water was splashed onto her tummy. 24.4 Layla sat upright in her chair and managed to sit comfortably for the play session. She grasped the maraca and puppet Cindy's nose throughout the session, maintaining a steady grasp.			
<b>Social</b>	<b>Focus:</b> Smiles Response to use of name	<b>Focus:</b> Smiles Familiarisation and response to use of name	<b>Focus:</b> Smiles Familiarisation and response to use of name Maraca shake- "Hurray"	<b>Focus:</b> Smiles Familiarisation and response to use of name Maraca shake- "Hurray" Glockenspiel tapping: "Hurray"
<b>Noticing/notes:</b>	24.4. Layla smiled when Cindy tried to "gobble" her fingers. Throughout the session, Layla smiled and giggled a number of times, especially when engaging with the nursery rhymes			
<b>Emotional</b>	<b>Focus:</b> Response to smile and safe, calm talk Familiarisation with new adult- Sue	<b>Focus:</b> Response to smile and safe, calm talk Self-soothing- floating in warm water	<b>Focus:</b> Response to smile and safe, calm talk Feeling safe: familiarisation with new adult- Sue	<b>Focus:</b> Response to smile and safe, calm talk Feeling safe: familiarisation with new adult- Sue
<b>Noticing/notes:</b>	24.4 Layla was happy to engage with the puppets and showed herself to be comfortable with a new adult.			
<b>Cognitive</b>	<b>Focus:</b> Introduce songs: Five little fingers- 1,2,3,4,5.	<b>Focus:</b> Introduce songs: Open/shut them- give a little splash (water) Put your finger on your nose	<b>Focus:</b> Introduce songs: Open/shut them- give a little shake (maraca) Put your finger on your nose Literature: Row, row, row your boat Environmental: Apple	<b>Focus:</b> Introduce songs: Hello Layla- new greeting song Open/shut them- give a little tap (glockenspiel) Put your finger on your nose Put a spot over here.... Literature: Row, row, row your boat
<b>Noticing/notes:</b>	24.4 Layla enjoyed the songs and showed anticipation of the "gobble" in open/shut them nursery rhyme by smiling a engaging in eye contact. She smiled and maintained eye contact during several parts of the songs, which we repeated throughout the sessions, showing early enjoyment and familiarity.			
<b>Language</b>	<b>Focus:</b> Making sounds/vocalising: coo Greeting- Hello Layla!	<b>Focus:</b> Self-labels: nose, eyes, mouth, chin Actions: splash shake, clap, hurray Commands: yes	<b>Focus:</b> Self-labels: nose, eyes, mouth, chin Actions: shake, clap, hurray, gobble Commands: yes Vocabulary: apple	<b>Focus:</b> Self-labels: nose, eyes, mouth, chin Actions: shake, clap, hurray, gobble Commands: yes Vocabulary: apple
<b>Noticing/notes:</b>	24.4 Layla was happy to engage with the nursery rhymes and smiled frequently. She enjoyed songs where she touched Cindy's eyes and nose as well as her own (guided by hand on hand). She vocalised regularly throughout the session, especially during the nursery rhymes.			
	<b>Resources:</b> Puppet play- Cindy	<b>Resources:</b> Puppet play- Cindy Sensory: perfumed flower	<b>Resources:</b> Puppet play- Cindy, HP Text: Row, Row, Row your boat Sensory: Maraca, Peek a boo- scarf	<b>Resources:</b> Puppet play- Cindy, HP Text: Row, Row, Row your boat Sensory: Maraca, glockenspiel Peek a boo- scarf

Layla loves music and music therapy. She really enjoys Greek folk dancing music and soft lullabies. She especially appreciates it when the music is combined with positive touch. Her massage therapist uses this to Layla's advantage when relieving her neck, thumbs and back from pressure points created by her low muscle tone.

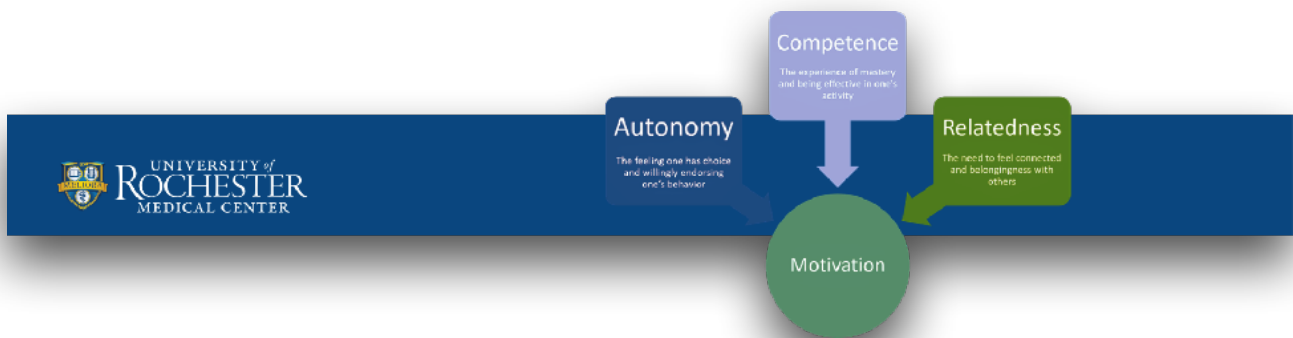


Layla loves physiotherapy and we are currently working on her vestibular sense, the use of her legs and hands, as well as her neck strength.



## Layla's Learning

We have a strong belief in Self-Determination Theory. We use its basic principles to help Layla grow and develop by meeting her needs for competence, autonomy and relatedness. This link to the University of Rochester Medical Centre unpacks the theory further:



<https://www.urmc.rochester.edu/community-health/patient-care/self-determination-theory.aspx>

We also base our work with Layla on the Learning Disposition Wheel from *4C Transformative Learning*.



<https://www.4ctransformativelearning.org/>

All of the processes from feeding to playing are always reflected upon in terms of the learning dispositions (see Page 14) and how they are emerging or developing in Layla.

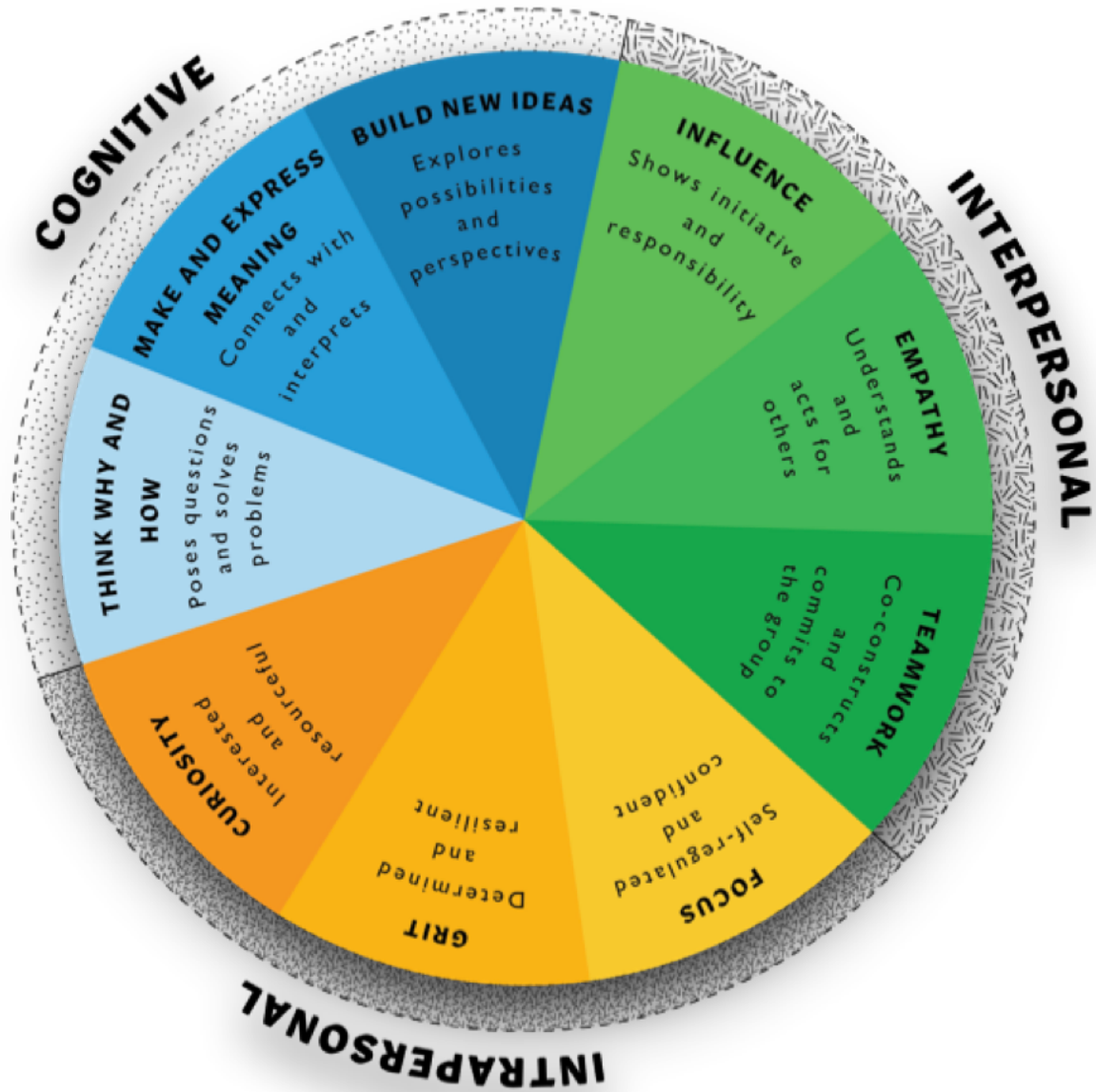


We are trying to feed her deep curiosity all the time. It is incredible how she tries to look and seek out all the stimuli around her. She loves scent and lavender is still her favourite.

We are also trying to get her to control her gaze and track things with her eyes better so that her neck also develops. We are using glow sticks as a novel way to engage that through her curiosity.



# Learning Disposition Wheel from 4C Transformative Learning







## Layla's SCN8A (Genetic illness)

Layla has a genetic 'misspelling' in the SCN8A gene in her DNA. This text from a quick Google search result is helpful:

*The SCN8A gene belongs to a family of genes that provide instructions for making sodium channels. These channels allow positively charged sodium (Na) atoms (sodium ions) to pass into cells; they play a key role in a cell's ability to generate and transmit electrical signals.*

<https://medlineplus.gov/genetics/gene/scn8a/#:~:text=The%20SCN8A%20gene%20belongs%20to,generate%20and%20transmit%20electrical%20signals.>

This means that her nervous system has problems with managing sodium and therefore isn't under her control.

This condition has two main phenotypes and Layla's is called Gain of Function (GOF). This means that her nerves flood with sodium and that they can not block it. This ends up with seizures and other co-morbidities as per the infographics below which have been ticked and highlighted to show what Layla has to battle with specifically.





# How Layla's SCN8A is more than Seizures



<b>Vision/Hearing</b>	<b>25%</b>
<del>Vision problems (cortical blindness)</del>	23%
Problems with hearing	7%
<b>Neurological</b>	<b>82%</b>
Hypotonia or low muscle tone	67%*
Ataxia/Cerebellar abnormalities	54%*
<del>High Pain Tolerance</del>	16%
Movement disorders	34%
<del>Spasticity, rigidity, or high muscle tone</del>	24%
Low Pain Tolerance	5%
<b>Developmental/Behavioral</b>	<b>92%</b>
Intellectual disability	68%*
Autistic Features	51%*
Sleep Difficulties	49%*
Agitation/irritability	47%
Social-behavioral or mood disorder	23%
Sleep disturbances increase seizures	20%
Autism spectrum disorder	14%
<b>Musculoskeletal</b>	<b>61%*</b>
Physical weaknesses	58%
Scoliosis (curvature of spine)	13%
Osteopenia (Frequent bone fractures)	10%



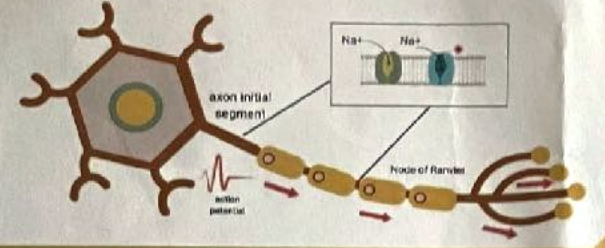
<b>Immune</b>	<b>29%</b>
Multiple pneumonias	27%
Unusual Fevers	5%
<b>Gastrointestinal</b>	<b>67%</b>
Constipation	44% *
Reflux	37%
Feeding problems	30%
Unsafe swallow	27%
Frequent vomiting	20%
Diarrhea	18%
<b>Autonomic</b>	<b>58%</b>
Cold hands and/or feet	36%
Temperature instability	30%
Increased sweating	26%
Decreased sweating	14%
Urinary retention	13%
Heart arrhythmia or heart rate changes	13%
Swelling	10%
Autonomic nervous system dysfunction	6%
<b>Other</b>	<b>19%</b>
Cutis marmorate (lacy rash)	10%
Abnormalities in any other organs	8%
Dysmorphic features	6%



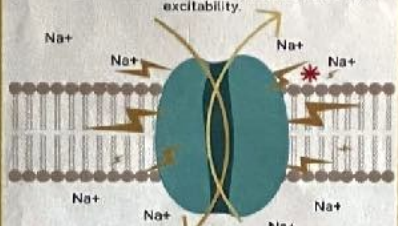
# Layla's Gain of Function (GOF) Phenotype

**LET'S EXPLORE**  
**Gain of Function**

Pathogenic SCN8A variants alter the biophysical properties of the Nav1.6 sodium channel and change the way that neurons communicate with each other




Gain of function mutations cause premature opening or impair inactivation of the Nav1.6 channel. This leads to **increased influx of sodium ions and excess neuronal excitability.**



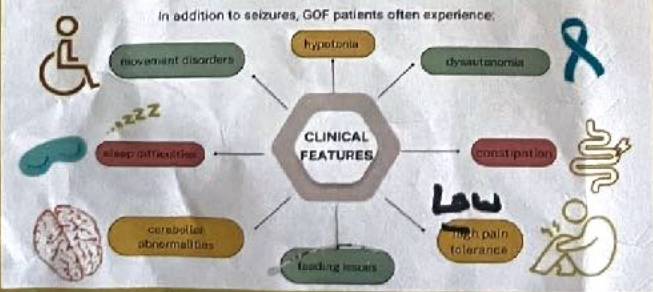
**99%**  
of GOF patients experience seizures

Sodium channel blockers are generally beneficial for individuals with gain of function mutations. Occasionally, patients benefit from the addition of medications with other mechanisms of action (e.g. gabaergic drugs or calcium channel blockers)

Most commonly prescribed sodium channel blockers are

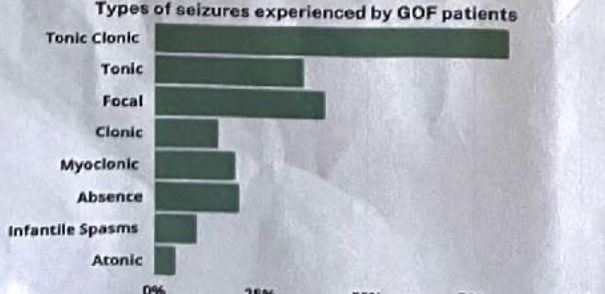


In addition to seizures, GOF patients often experience:



**CLINICAL FEATURES**

**Types of seizures experienced by GOF patients**



Seizure Type	Percentage
Tonic Clonic	~85%
Tonic	~45%
Focal	~45%
Clonic	~25%
Myoclonic	~25%
Absence	~25%
Infantile Spasms	~15%
Atonic	~5%

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## Layla's Pain Scale

Layla is severely affected and has levels of pain and suffering, with distinctions detailed for seizures to ensure that the teams working with her understand her and treat her accurately.

0

- BPM < 65
- Relaxed shoulders
- Soft abdomen
- Jittering - None



1

- BPM 75 Faster breathing
- Noisy breathing
- Shoulders slightly rolled forward
- Jittering - mainly upper limbs
- Abdominal distention or firm to touch



2

- BPM > 75 Continued fast breathing
- Arms side movements - mainly forward



3

- Faster breathing/panting
- Shoulders rolled forward
- Arms side movements and full pronation
- Thumbs in
- Hard abdomen with very noticeable distention



4

- Faster breathing/panting
- Crying
- Shoulders rolled forward
- Arms side movements
- Thumbs in with clenched fist
- Hard abdomen with very noticeable distention
- Light pulsing of abdominal and others around the belly





5

- Faster breathing/panting
- Cries and screams
- Arms side movements
- Thumbs in with clenched fist
- Legs and feet twitching or moving too
- Hard abdomen with very noticeable distention
- Distinct pulsing/contractions and release of abdominal and others around the belly





<p>6</p>	<ul style="list-style-type: none"> <li>• Faster breathing/panting</li> <li>• Intermittent cries; and screams</li> <li>• Arms side movements</li> <li>• Thumbs in with clenched fist</li> <li>• Legs tense and toes curl</li> <li>• Hard abdomen with very noticeable distention</li> <li>• Intense pulsing/contractions and release of abdominal and others around the belly (can be see through clothes)</li> </ul>	
<p>7</p>	<ul style="list-style-type: none"> <li>• Faster breathing/ breathless panting</li> <li>• Cries and screams</li> <li>• Arms side movements</li> <li>• Thumbs in with clenched fist</li> <li>• Legs tense and toes curl</li> <li>• Intense pulsing/contractions and release of abdominal and others around the belly (can be see through clothes)</li> </ul>	<p>More intense like volume and screaming until she is starting to change colour</p> <p>Often no tears left</p>
<p>8</p>	<ul style="list-style-type: none"> <li>• Faster breathing/ breathless panting</li> <li>• Screams varying in volume</li> <li>• Arms side movements</li> <li>• Thumbs in with clenched fist</li> <li>• Legs tense and toes curl</li> <li>• Hard abdomen with very noticeable distention</li> <li>• Intense pulsing/contractions and release of abdominal and others around the belly (can be see through clothes)</li> <li>• Whole body stiffens</li> </ul>	<p>She is now in a very intense response</p>

9	<ul style="list-style-type: none"><li>• Breathless panting</li><li>• Continuous screams varying in volume</li><li>• Arms side movements</li><li>• Thumbs in with clenched fist</li><li>• Legs tense and toes curl</li><li>• Stiffening back</li><li>• Eyelids start to flutter</li><li>• Hard abdomen with very noticeable distention</li><li>• Intense pulsing/contractions and release of abdominal and others around the belly (can be see through clothes)</li></ul>	
10	<ul style="list-style-type: none"><li>• Breathless panting</li><li>• Continuous screams varying in volume</li><li>• Arms side movements</li><li>• Thumbs in with clenched fist</li><li>• Legs tense and toes curl</li><li>• Intense pulsing/contractions and release of abdominal and others around the belly (can be see through clothes)</li><li>• (scratch her sole and get her to focus on something and if she responds it irritability - if not - it's a seizure)</li></ul>	<p>Compare this to seizure videos and chart</p>

## Layla's Seizures

- Starts with a big gasp and scrunched up face
- Stiffening back
- Eyelids start to flutter in rhythmic pattern
- Eyes fixed gaze to one direction usually to the left/sometimes wanders aimlessly and cannot move to stimulus
- Rhythmic panting with clear sound just grunting
- Desaturation at the start at times and usually resolves in seconds
- Upper limbs show tonic state with either both shoulders internally rotated with extremely small oscillating movements
- At times an arm independently, or both together can show slight clonic state
- Motley colour and turns blue toned





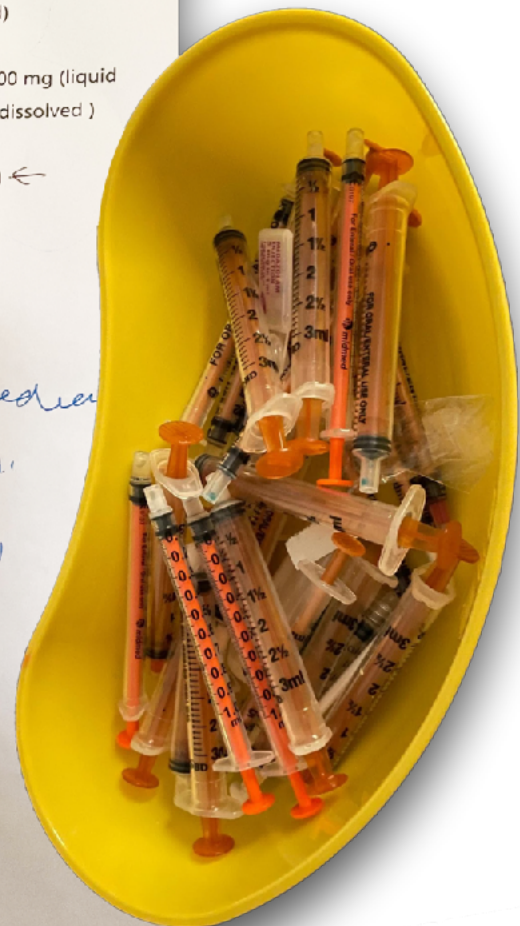
## Layla's Medication Regime

Layla's medication regime is demanding and complex, both for her and her carers. It includes anti-epileptics, sedatives, pain relievers and a gastro-intestinal suite of drugs. There are regular drugs and they change in dosage according to weight or how ill she is. There are also drugs that we need to use to relieve pain and/or get her to sleep, again, based on just how ill she is each day. The poster and picture below show you the drugs as of the 5 March 2023. Many of these are crushed, mixed and prepared by us at home, and prepared four times a day.

5/3/23

Layla

<p><del>0700</del> 5am</p> <p>Clonazepam, 0.2 mg (2 drops)</p> <p>gabapentin, <del>75</del><sup>100</sup> mg, (capsule)</p> <p>lacosamide 15 mg (liquid)</p> <p>omeprazole, 8 mg (liquid/ tablet)</p> <p>OsmoLax, 1 small scoop</p> <p>phenytoin <del>50</del><sup>75</sup> mg (tablet/ capsule)</p> <p>folic acid, 0.5 mg, (tablet)</p> <p>topiramate, 18.75 mg (Tablet)</p> <p>+ Clonidine 7.5mg 0.35ml</p> <p><del>1400</del> 12noon</p> <p>Clonazepam, 0.2 mg (2 drops)</p> <p>Gabapentin <del>75</del> mg, (capsule)</p> <p>Phenytoin 25 mg (capsule / tablets)</p> <p>Clonidine 7.5 mg 0.35ml</p> <p><del>1900</del> 5pm</p> <p>Lacosamide 15 mg (liquid)</p> <p>Omeprazole, 8 mg (tablet/ liquid)</p> <p>OsmoLax, 1 small scoop</p> <p>Topiramate, 18.75 mg (tablet)</p> <p><del>2200</del> 8pm</p> <p>Clonazepam, 0.4 mg (4 drops)</p> <p>gabapentin, <del>150</del><sup>175</sup> mg (capsule)</p> <p>phenytoin 50mg (capsule/ tablet)</p> <p>00:00 Clonidine 7.5 mg 0.35ml</p>	<p>PRN</p> <p>Paracetamol 85.8mg(liquid)</p> <p><input checked="" type="checkbox"/> Clonidine 10mcg (liquid)</p> <p><input checked="" type="checkbox"/> Chloral Hydrate 200mg / 100 mg (liquid)</p> <p><input checked="" type="checkbox"/> Ondansetron 1mg (wafers dissolved )</p> <p><input type="checkbox"/> Glycerol infant suppository</p> <p><input type="checkbox"/> Midazolam 1.7mg ( liquid ) ←</p> <p><input type="checkbox"/> Gavison infant sachet.</p> <p style="margin-top: 20px;">Clonidine</p> <p style="margin-left: 20px;">0</p> <p style="margin-left: 20px;">9</p>
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## Layla's Sudden Changing Needs

Layla's SCN8A genetic disease means that all the nerves in her body do not work properly, so she has ever changing needs based on where she is most affected at any given time. Her muscular-skeletal system is challenged with a movement disorder; her cardio-vascular system is stressed with sudden raised heartbeats and tachypnoea; her central nervous system is always unstable, with regular bouts of seizures and extreme pain that can last for a few seconds to half an hour; and her entire digestive system has issues with reflux, vomiting, digestion, motility, and excretion.

When we try to solve one issue, we can exacerbate another or create an imbalance. Hence Layla is like a tricky puzzle, much like Rubik's cube. When you only try to solve one side the other sides will not match, so like Layla, all things must be considered to get the best possible well-being.



The table below demonstrates how varied her sleep, seizure and pain are daily. It also shows us how much we rely on extra medications to support Layla, as well as how clinical decisions regarding what to give her and when are required every day.

Parents with children that have SCN8A have a dark joke they sadly share. There are a few versions much like this one, 'Having a child with SCN8A is like having PTSD but it stands for PERSISTENT TRAUMA STRESS DISPOSITION. This is our experience too, in that we are always responding to an emergency while trying to live as much of a rich life as possible. We rely heavily on the support around us and are only just managing with it.





## Layla's Sudden Changing Needs Table

Layla's Sudden Changing Needs, A Daily Snapshot March to April 2023

Date	Seizures	Pain & Irritability	Sleep	Eating	Extra Medication	Hospital
19/03		Extreme	4 Hrs	Yes	Panadol Clonidine Chloral Hydrate	
20/03	2	Extreme	4 Hrs	Yes	Panadol Clonidine Chloral Hydrate Midazolam	Yes
21/03	1	Extreme	4 Hrs	Yes	Panadol Clonidine Chloral Hydrate Midazolam	
22/03	4	Moderate	6.5 Hrs	Yes	Panadol Clonidine Midazolam	
23/03		Mild	6 Hrs	Yes	-	
24/03	7	Moderate	No record	No	Midazolam	
25/03	3	Moderate	7 Hrs	Yes	Panadol Clonidine Chloral Hydrate Midazolam	Yes
26/03		Mild	8 Hrs	Yes	Panadol Clonidine Chloral Hydrate	
27/03		Low	15 Hrs	Yes	Panadol	
28/03		Mild	5.5 Hrs	Yes	Panadol Clonidine Ondansetron	
29/03	6	Moderate	4 Hrs	Yes	Panadol Clonidine Midazolam	
30/03		Mild	5 Hrs	Yes	Panadol	
31/03	7	Moderate	4 Hrs	Yes	Panadol Clonidine Midazolam Ondansetron	

## Layla's Sudden Changing Needs, A Daily Snapshot March to April 2023

Date	Seizures	Pain & Irritability	Sleep	Eating	Extra Medication	Hospital
01/04		Mild	6 Hrs	Yes	Panadol Clonidine	
02/04		Mild	7 Hrs	Yes	Panadol Clonidine Chloral Hydrate	
03/04		Moderate	3 Hrs	Yes	Panadol Clonidine Midazolam Ondansetron	
04/04	2	Mild	7 Hrs	Yes	Panadol Clonidine Midazolam	
05/04		Mild	8 Hrs	Yes	Clonidine	
06/04	4	Moderate	4 Hrs	Yes	Panadol Clonidine Midazolam	
07/04	2	Moderate	1.3 Hrs	Yes	Panadol Clonidine Midazolam	Yes
08/04		Moderate	9 Hrs	Yes	Panadol Clonidine	
09/04		Moderate	6.5 Hrs	Yes	Panadol Clonidine	
10/04		Mild	4 Hrs	Yes	Panadol Clonidine	
11/04		Extreme	4 Hrs	Yes	Panadol Clonidine Chloral Hydrate	
12/04		Extreme	3.5 Hrs	Yes	Panadol Clonidine Chloral Hydrate	
13/04		Moderate	5 Hrs	Yes	Panadol Clonidine Chloral Hydrate	
14/04		Mild	8 Hrs	Yes	Panadol Clonidine Chloral Hydrate	

## Layla's Sudden Changing Needs, A Daily Snapshot March to April 2023

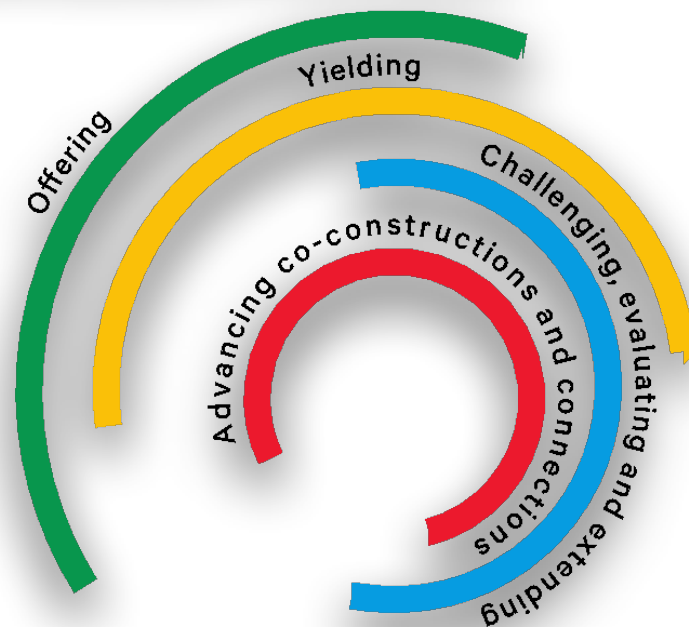
Date	Seizures	Pain & Irritability	Sleep	Eating	Extra Medication	Hospital
15/04		Mild	7 Hrs	Yes	-	
16/04		Moderate	6.5 Hrs	Yes	Panadol Clonidine	
17/04		Moderate	5 Hrs	Yes	Panadol Clonidine	
18/04		Mild	8 Hrs	Yes	-	
19/04		Mild	7 Hrs	Yes	Panadol Ondansetron	
20/04		Moderate	6 Hrs	Yes	Panadol Clonidine Chloral Hydrate Ondansetron	
21/04		Moderate	8 Hrs	Yes	Panadol	
22/04		Moderate	8.5 Hrs	Yes	-	



## Working with the Teams that Serve Layla

We work with this schema for collaboration from *4C Transformative Learning*.

# Collaboration Circles



We prefer that all things are considered and worked towards through co-construction and communication.

We understand that there are 'captain calls' that need to be made at times but we expect that that is made explicit to us including the reasoning for it.

## Layla's Goals and NDIS



### **Goal A** Develop early language and communication skills

- We are working with Cerebral Palsy Alliance to provide supports and other services to maximise her communication which needs intense attention.
- We are ensuring that the teams around Layla are sharing information and any cues that they understand that Layla uses.
- The teams alertness to Layla and their deep noticing of her needs are being fostered in regular reflection meetings at all levels.

### **Goal B** Develop endurance strength and gross motor skills

- The natural history of Layla's condition is that she will be non-ambulatory, non-verbal and feed from a tube but we are having successes in feeding due to hard work and careful time consuming persistence.

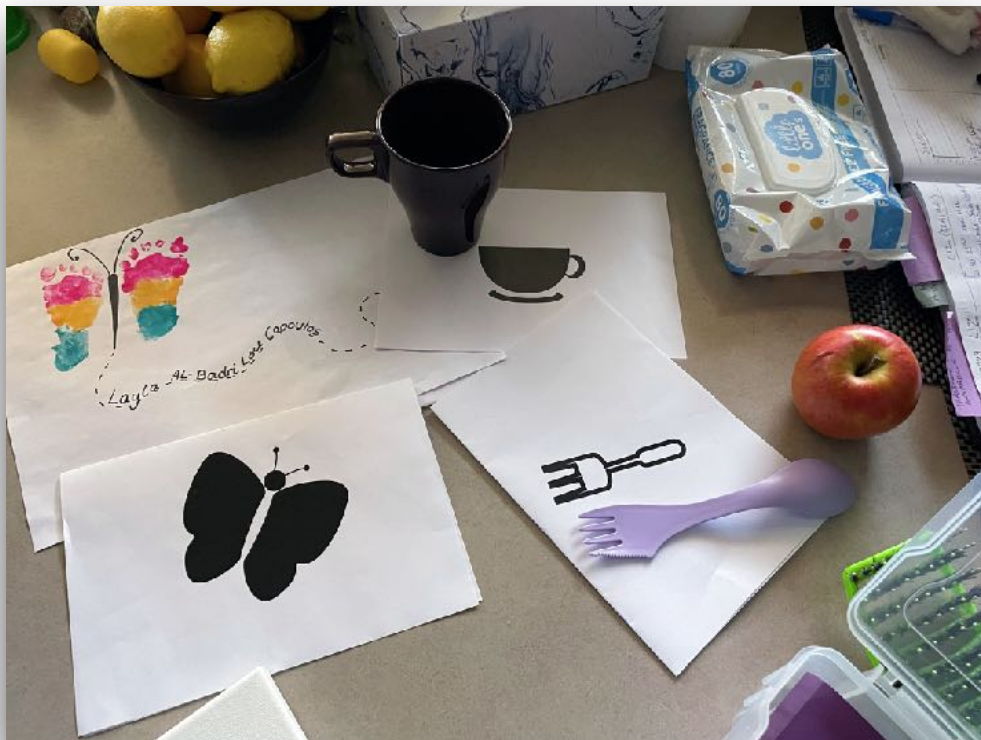
- We are working on the use of her hands and legs and the back of her neck and vestibular sense. This takes up all the day, if we are not feeding. It is done through processes of play.

### Goal C Social and emotional development

- Layla's opportunities to sit at the dinner table, engage in cooking processes e.g. hold a cut lemon are being focussed upon.
- We foster play with her sister that is rough enough to be fun but are very careful and hands on.
- We take her out to galleries in particular as she loves visual arts.

### Goal D Learning and cognitive development

- We are focussing on labelling and collecting key words such as yes and no. The words are used in processes such as painting or eating always.





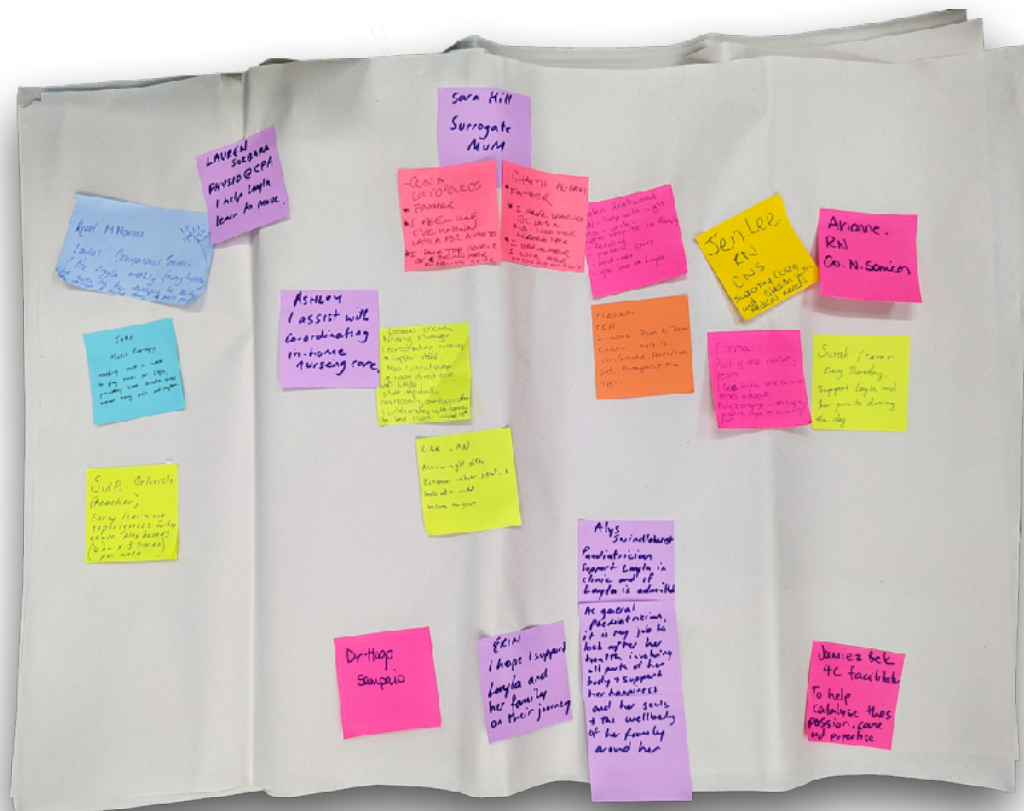
# Interdisciplinary Meeting

The first facilitated interdisciplinary meeting for Layla:

Layla's Team Meeting Thursday 13 April  
Cerebral Palsy Alliance  
469 Forest Road Penhurst NSW 2222  
1:30pm - 4:30pm

It was facilitated by *4C Transformative Learning* to ensure that all 'voices' were given equal weight, including the parents.

The three hour meeting was attended by almost all her team. A map of the ecology or architecture of practice was created:



## FAMILY

Parents

**Dr Ghaith Al-Badri**    **Mr Costa Loucopoulos**

Sibling

**Pan Al-Badri Loucopoulos**

Grandparent

**Ms Panagiota Loucopoulos**

Gestational Carrier

**Ms Sara Hill**

## CEREBRAL PALSY ALLIANCE

Head Physiotherapist

**Ms Lauren Sorbara**

Occupational Therapist

**Mrs Renee McNamara**

Speech Pathologist

**Amanda Khamis**

## CRONULLA NURSING SERVICE

Director

**Ms Vanessa McKirdy**

Registered Nurses

**Ms Arianne Americanos**

**Ms Ashley Gustavs**

**Ms Helen Heathwood**

**Ms Jen Lee**

**Mr Luke Brown**

Enrolled Nurses

**Ms Elizabeth Campbell**

**Ms Emma Sutherland**

Training Nurse

**Ms Sumana Karki**



Layla

## THERAPISTS

Early Learning Specialist

**Ms Sue Orlovich**

Music Therapists

**Mr Jake Magi**

**Ms Renee King**

Massage Therapist

**Ms Emma Phelps**

## HOSPITALS

Sydney Childrens Hospital

Neurologist

**Dr Hugo Sampaio**

Epilepsy Clinical Nurse Consultant

**Erin Beavis**

Sutherland Hospital

Head of Paediatrics

**Dr Alys Swindlehurst**

## 4CTL

4C Transformative Learning

Director of Operations

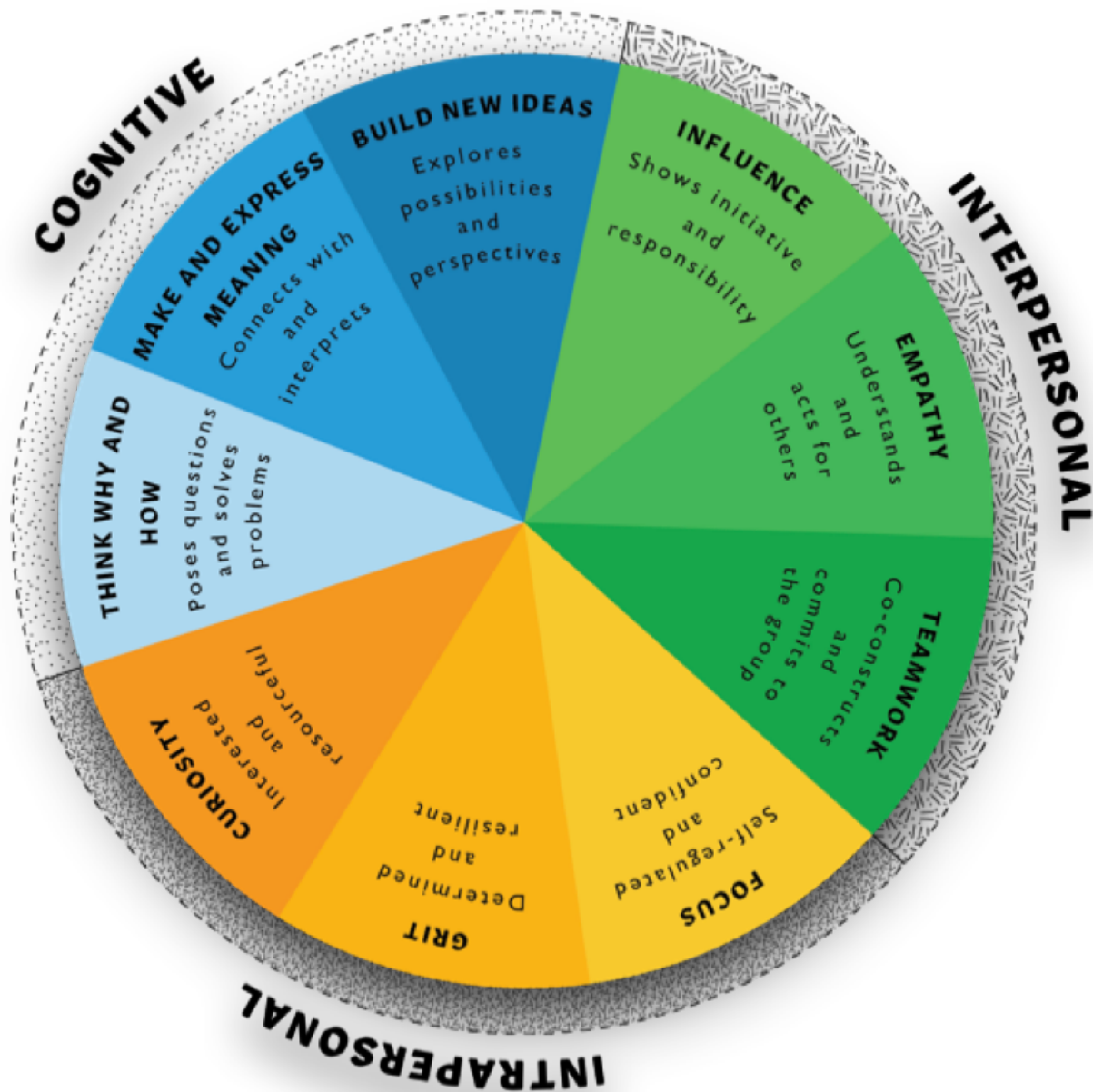
**Mr Jamie Gerlach**

Senior Practice Leader

**Ms Rebekah Palmer**

Participants also connected with their individual goals for Layla and saw how they can maximise the outcomes we share for her through communication and collaboration. They also reflected on their own learning and the personal skills that they draw upon to be most effective.

Participants were introduced to the *Learning Disposition Wheel* and asked to reflect in written logs that they have kept to continue reflecting.



## Interdisciplinary Meeting Outcomes

- Communication is streamlined
- A dictionary of Layla has been started
- Participants are outcomes focussed and willing to safely experiment to get them
- Layla has become the focus of all cross disciplinary discussion (not just her illness)
- Layla has been further humanised and understood

## Metaphor and common understanding: The pot called Layla

Helen Heathwood is a nurse that cares for Layla, and she is an artist as well. She made a pot for Layla. It broke in the process of being made and she took the opportunity to use the Japanese art form of Kintsugi (repairing broken clayware to highlight the beauty of it break).





The metaphor is best explained in her card as she extends it beautifully by relating the processes of pottery to the trimesters in pregnancy.

<p><u>I Made a Pot -</u> <u>I called it Layla</u>          After refining the pinching process with clay I wanted to make a series to be glazed with different colours on the inside. I started by making 3 small bowls of similar size. I spent hours pinching the shapes and refining the form. Finally, they were ready for the 1st firing. They survived the first firing in perfect condition.          I then prepared them for the glaze firing with a different colour inside each pot. One orange one blue, the other green. All 3 pots came out of the glaze firing broken. Not just cracked but broken into many pieces. Not what I expected but this sometimes happens. I reassembled all the pieces and they fitted back together perfectly and the cracks actually formed a pleasing pattern around the pot. Someone told me about an ancient Japanese Art form called "Kintsugi" where broken pottery can be</p>	<p>repaired with gold. Kintsugi is considered the oldest technique for repairing broken pottery. It is a beautiful way to repair broken pottery. I started the art form and learnt how to do it. It is a tedious process but I really did it and made my own beautiful pot. The different shaped pieces came together perfectly being made stronger by the golden clay which held them in place.          Have we not all come together as pieces of the puzzle with our contribution in our own brokenness? We are held together with our individual skills and our intention for Layla and her family.          I called this pot Layla. Much love, planning, cooperation and effort has gone into the manifestation of this child. She didn't emerge the way it was originally perceived. She is a magical human being. I don't see her as broken. There is something supremely precious and beautiful about her. Layla is this beautiful pot and all the precious new beings</p>
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I Made a Pot - I called it Layla

After refining the pinching process with clay I wanted to make a series to be glazed with different colours on the inside. I started by making 3 small bowls of similar size. I spent hours pinching the shapes and refining the form. Finally, they were ready for the 1st firing. They survived the first firing in perfect condition.

I then prepared them for the glaze firing with a different colour inside each pot. One orange one blue, the other green. All 3 pots came out of the glaze firing broken. Not just cracked but broken into many pieces. Not what I expected but this sometimes happens. I reassembled all the pieces and they fitted back together perfectly and the cracks actually formed a pleasing pattern around the pot. Someone told me about an ancient Japanese Art form called "Kintsugi" where broken pottery can be

I made a Pot - I called it Layla

After refining the pinching process with clay I wanted to make a series to be glazed with different colours on the inside. I started by making 5 small bowls of similar size. I spent hours pinching the shapes and refining the form. Finally they were ready for the 1st firing. They survived the first firing in perfect condition.

I then prepared them for the 2nd firing with a different colour inside each pot. One was blue, the other green. All 5 pots came out of the kiln firing broken. I just cracked but broken into many pieces. Not what I expected but this sometimes happens. I reassembled all the pieces and they fit back together perfectly and the cracks actually formed a pleasing pattern around the pot. Someone told me about an ancient Japanese Art form called 'Kintsugi' where broken pottery can be repaired with gold. It's philosophy is to celebrate the object taking on a new life being stronger and more beautiful than the original concept.

I studied the artform and learnt how to do it. It's a tedious process but I finally did it and made my 1st Kintsugi pot. The different shaped pieces came together perfectly being made stronger by the golden veins which hold them in place.

Have we not all come together as pieces of the puzzle with our contribution in our own brokenness? We are held together with our individual skills and good intentions for Layla and her family.

I called this pot Layla.

Much love, planning, cooperation and effort has gone into the manifestation of this child. She didn't emerge the process the way it was originally perceived. She is a whole human being. I don't see her as broken. There is something supremely precious and beautiful about her.

This is why (Ghazith and Costa) this small pinch pot and all it represents now belongs to you xx

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Helen's presentation ended the session reminding us all that there is real hope in our work and to find the beauty of Layla's life and Layla's milestones.

*"...there is real hope in our work...to find the beauty of Layla's life and Layla's milestones."*

Ghaith & Costa