

# Tiny Life Cares

Strategic Plan 2022-2025




**Tiny  
Life.**  
Northern Ireland's  
only premature baby charity



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A photograph of a newborn baby being held by a person, with a medical professional in the background. The image is overlaid with a semi-transparent red filter. The baby is wrapped in a white blanket and is being held against the person's chest. The medical professional is wearing a white coat and a stethoscope.

Every year in Northern Ireland over **1900 babies** are born too soon, too sick or too small and may have to spend time in one of the seven neonatal units



# Forward from our Chair



The TinyLife team including the Board, Management, our employees and volunteers are committed to be at their best every day in service to our babies, parents and families. To achieve this, we set ourselves high quality standards and live our values in all that we do.

We ensure our way of working reflects the ethical standards set out in the legal framework within which we operate, knowing that this will enable us to better fulfil our responsibilities.

We believe in working together as one team, and creating a culture where we will look out and care for each other, encourage diversity of thought and create the conditions in our Charity to advance our Mission for all we serve with a focus on babies, parents and families.

# Our Strategy 2022-2025

TinyLife's strategy for 2022- 2025 builds on 30 years' experience of supporting parents and families from across Northern Ireland, optimising birth outcomes for premature or sick babies who start life in a neonatal unit.

Every year in Northern Ireland over 1900 babies are born too soon, too sick or too small and may have to spend time in one of the seven neonatal units. TinyLife is Northern Ireland's only charity supporting families of babies born prematurely or who will start life in a neonatal unit. We provide support services within the neonatal units, family homes and in local communities.

We are dedicated to helping reduce the impact of being born premature or spending time in a neonatal unit, on both the baby and family. From our earliest days, as the Northern Ireland Mother and Baby Appeal (NIMBA), we have worked in collaboration with universities and others to support

groundbreaking medical and social research. The outcomes of many of these research projects have helped shape advances in the care of newborn infants and the services we, in TinyLife provide.

The experiences that families face and the story of their journey from the neonatal unit to home and throughout their baby lives is vital to understanding how we and others can make a difference. Therefore, we provide a platform for the voice of parents of premature babies to be heard. We listen to these concerns and represent their needs when advocating, campaigning and lobbying for change and improved services





# Our Vision, Mission & Values

## Mission

“Our Mission is that a **premature or sick baby who starts life in a neonatal unit in Northern Ireland has the best start to life and is supported to reach their full potential**”.




## Vision

To achieve this we will support, advocate and champion for their **rights** to receive the **best support** in the right place and at the right time for them, from birth to preschool. We achieve this by **empowering families, collaborative working and influencing practice and policy.**

***“TinyLife supports, advocates and champions the right for every baby born premature or who starts life in neonatal unit to have their best start to life and to receive the best support in the right place for them, from birth to preschool. We achieve this by empowering families, collaborative working and influencing practice and policy.”***

## Our Values

	What we value	Behaviours
Parents, Families	Empowerment	<p><b>Tinylife strives to understand the individual needs of families, coming alongside them to provide education, support and advice, giving them the vital tools to care for their babies with confidence and pride.</b></p> <ul style="list-style-type: none"> <li>· We are empowered to always look for a better way to do things</li> <li>· We are empowered to be relentless in the pursuit of quality and safety and strive for excellence in all we do</li> <li>· We are empowered to achieve our goals, and go the extra mile</li> </ul>
Babies Health Care Professionals	Learning	<ul style="list-style-type: none"> <li>· We work to continuously improve our own strengths and build our knowledge base</li> <li>· We commit to doing what it takes to know ourselves and impact on others</li> </ul>
	Nurturing	<p><b>Tinylife will provide a safe space in which families feel protected and cared for, enabling them to reach their full potential.</b></p> <ul style="list-style-type: none"> <li>· We nurture ourselves so we can nurture others</li> <li>· We put team results before own success, acknowledge contribution of others</li> <li>· We value humility, caring, trust, respect and empathy</li> </ul>
Team	Courage/Bravery	<p><b>We continue to keep the needs of the families at the very heart of what we do and be their voice in protecting rights</b></p> <ul style="list-style-type: none"> <li>· Speak up and challenge the norm, giving and receiving feedback</li> <li>· Acknowledge when things don't work and learn to grow and build</li> <li>· Give and accept constructive feedback</li> <li>· We take on the difficult conversations</li> </ul>
	Integrity	<p><b>Together we strive to do the right thing, at the right time, with the right resources.</b></p> <ul style="list-style-type: none"> <li>· Operate with high ethical standards</li> <li>· Live by the Code of Conduct even when facing resistance or difficulties</li> <li>· We advocate and apply high ethical standards every day</li> </ul>
Self	Inclusivity	<p><b>We endeavour to provide friendly and welcoming support to all families making our service accessible to every parent and baby in need.</b></p> <ul style="list-style-type: none"> <li>· We aim to walk every day in the shoes of our parents and health care professionals</li> <li>· We care about diversity and will ensure we reach all communities across Northern Ireland</li> <li>· We champion working together and with our partners</li> <li>· We welcome diversity and inclusion of styles, ideas and perspectives</li> </ul>



TinyLife supports, advocates & champions the right for every baby born premature or who starts life in a neonatal unit to have their best start to life & to receive the best support in the right place for them, from birth to preschool. We achieve this by empowering families, collaborative working & influencing practice & policy.

# Why we exist

Each year in Northern Ireland **OVER 1,900** babies are born prematurely or sick and require neonatal support.

Even as outcomes for newborn infants improve, parents and families still face **UNIQUE & DIFFICULT** challenges due to the associated **TRAUMA AND IMPACT** on their mental health and wellbeing & their situation & circumstances.

**80%** of babies who die within the first 28 days are premature, **WITH 4.7 STILL BIRTHS PER 1,000 BABIES BORN.**

**79%** of parents felt their mental health had been negatively impacted,

**46%** of parents suffered relationship difficulty,

**54%** of parents felt their older children were also negatively impacted by the neonatal journey.



# Caden & Laura's story



Caden was born 09.09.19 at 14:55 weighing 1lb 10oz, at just 24 weeks and 6 days. There was no life. No sound. He was resuscitated for 20 minutes by one of the consultants in the room, with her finger. She, and her team of 14 nurses and doctors never gave up.

Caden spent 119 days in Intensive Care, 7 days in High Dependency and 36 days in Special Care within the Neonatal unit. He then spent a further 3 days in the Children's Hospital and an additional 18 days back in Intensive Care.

Caden now lives with Cortisol Deficiency, Diabetes Insipidus, Underactive Thyroid and Stage 4 kidney disease. Caden sees an Endocrine consultant, a Renal Consultant, and a Physio. Caden has a personal dietician, the family attend a neuro development clinic, a child development clinic and he sees an Occupational Therapist.

Caden's parents describe Caden as their 'Miracle Baby.' All these professional people contribute to Caden's survival and happy self today. Caden attended services online family support TinyLife during lockdown online to include Baby Massage and TinyTime. Caden and his family still remain a friend of TinyLife, and we have regular contact.

## What we do

*Through our work for premature and babies who start life in a neonatal unit we strive to:*

- Provide a stimulating, rewarding family support group for families
- Support the attachment & bonding of premature & sick babies with their parents
- Promote good positive infant mental health.
- Support families of premature babies to feel more confident in their interactions with their children.
- Assist the families in support of their children to reach the developmental milestones closer to the stage of development of those who were born at full term.
- Represent the needs of parents, lobbying for change & improved services.
- Support research to shine a light on key issues faced by premature babies & their parents.

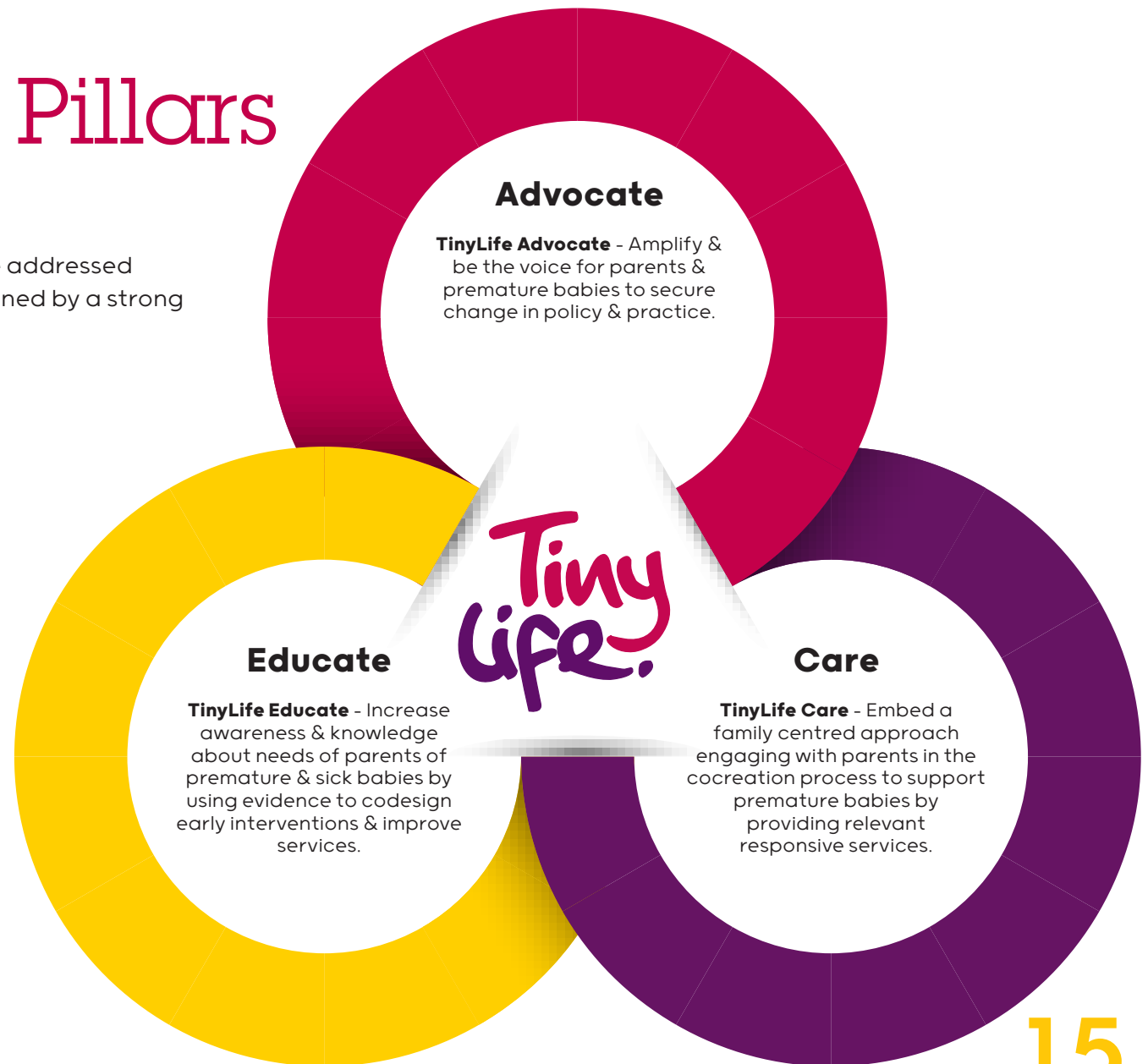


# Key Services for Families

Care	Educate	Advocate
Breast pump loan service providing mothers with opportunities to provide breast milk for premature babies which is crucial for growth & development	One-to-one telephone support, information sharing & signposting	Research with a range of key institutions including Queens University Belfast to provide insight into needs of premature babies and their families.
Family Support Officer weekly Neonatal Unit visits - providing parents with essential support including advice & practical support	TinyTime groups - parent & baby groups facilitated by TinyLife Family Support Officers allowing parents/ families of premature babies to connect & socialise.	Advocacy and lobbying work with government & agencies to ensure premature babies are on strategic agendas.
Baby Massage (International Association of Infant Massage accredited) to support attachment, bonding, sleep & minor medical conditions.	Parent Advisory Group to act as parent representatives.	
	TinyStart - Homebased parent education programme focusing on helping premature babies to meet their developmental milestones.	
	TinyGym - a specialist group delivered in the Northern Health & Social Care Trust (NHSCT)	
	Positive Minds for Premature Parents Project.	

# Three Core Pillars

The priorities for TinyLife for 2022-2025 are addressed under three core pillars which are underpinned by a strong governance and monitoring framework.



# 1 Care

We know the impact that having a premature or sick baby can have on parents and the wider family unit. Everyday life for families of premature and sick babies can be extremely challenging, and we understand the need to care for and support parents and families through their neonatal journey and to experience the joy of the birth their baby. TinyLife will continue to provide vital, timely support services which have been co-designed and developed in response to the needs of babies and families. We will listen to the needs of our service users and provide support in ways which are sensitive, accessible, inclusive, compassionate, and relevant to their specific needs.

**We will embed a family centered approach engaging with parents in the co creation process to support premature babies by providing relevant responsive services.**

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**What we want to achieve**

**Parents and Families**

- Extend the age criteria for support from age 2 to preschool
- Implement new evidence informed & evidence-based programmes into the Family Support Care pathway
- Develop & implement a digital platform of web-based services & support to increase parental choice & inclusion

**Staff**

- Build capacity & increase staff knowledge on best practices & evidence informed programmes
- Build & develop a team reflecting the diversity of the families we support
- Increase volunteers & self help

**Professionals**

- Support Neonatal Units to continue with the implementation of the model of Family Integrated Care post Covid

**Other**

- Partner with others to widen the reach of services to those in need

**How will we know we are making a difference**

- Monitoring trends in parental experience including uptake and outcomes of TinyLife services
  - Establishing and monitoring quality standards
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# 2 Educate

TinyLife prioritizes championing the rights of premature and sick babies and their families to receive the best possible support and services. We aim to educate and increase the knowledge and skills of parents, staff, professionals and volunteers to ensure services are designed in an effective and impactful manner, with the needs of premature babies, their parents and families at the heart. We will make certain the information we share, our resources, programmes and services are co-designed and evidence-based, delivered by staff who are skilled and empowered to make change happen and guided by effective governance and management to ensure an impactful, resilient and sustainable organisation.

**We will increase awareness & knowledge about effective support for parents of premature & sick babies by using evidence to co design early interventions & improve services.**

**What we want to achieve**

**Parents and Families**

- Raise awareness of the impact of prematurity
- Expand reach to those who need us via an enhanced TinyLife and Life At Home website
- Deliver evidence informed and evidence-based programs to underpin services

**Staff**

- Develop high performing staff teams who are nurtured & empowered to deliver high quality services
- Shape international best practice & ensure the views of Northern Ireland are well represented
- Develop our capacity to improve our services
- Build a high performing team with experienced staff through effective recruitment, training, and supervision

**Professionals**

- Support the implementation of training for neonatal staff & health visitors

**Board**

- A leading-edge governance and financial framework to enable the growth of TinyLife services and secure future resources ensuring a sustainable & resilient organisation.

**How will we know we are making a difference**

- Impact measures, quality standards & controls
- Parent Quality services
- Parents recommend us to other parents
- Agile, highly trained team



# 3 Advocate

We know it is vital to listen to parents & families & act as a strong voice, championing every premature or vulnerable baby & their family, representing their needs & lobbying for change. TinyLife knows the importance of working with parents & stakeholders to improve care & services & our policy work & research provides a vital insight to truly understand the needs of premature babies & their families, providing better outcomes for all & working to improve quality of life for many years to come.

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## **We will amplify & be the voice for parents & premature babies to secure change in policy & practice**

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### **What we want to achieve**

#### **Campaigns**

- Introduction of legislation for Flexible School Starting Age
- Engage with international campaigns on World Prematurity Day
- Support Zero Separation
- Support Breast Feeding
- Introduce the Prem Aware Award

#### **Representation**

- Be a sought after representative of the voice of parents in the development of key strategic frameworks for Infant Mental Health, Perinatal Mental Health and Neonatal Services

#### **Parental Engagement**

- Drive parental representation on key policy forums in Northern Ireland and Europe
- Strengthen opportunities for parental co design and co-production in services, policies and practices
- Support opportunities for engagement in research

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### **How will we know we are making a difference**

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- Increased access to services and self-referral
- Improved outcomes for babies





Assist the families in support of their children to reach the developmental milestones closer to the stage of development of those who were born at full term.

# Looking Ahead

TinyLife has identified the following principles as key to the successful implementation of this Strategic Plan. These will be respected in all aspects of our work in delivering the strategy outlined.

## Principles

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We aim to be operationally excellent & financially resilient, focused on maintaining a diverse range of income streams & fundraising efforts.

We want to develop an agile, skilled, empowered workforce who are confident & capable of nurturing & providing high quality service to all our families

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We are always focused on improving governance & building a knowledgeable, skilled & competent Board of Trustees respected for their strategic leadership & direction & differentiated by their care & compassion.

We strive to be an innovative organisation, making best use of digital technology & hybrid models of service delivery to meet our diverse client need.

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We are driven by a commitment to continuous learning & improvement, doing what it takes to know ourselves & our impact on others. Guided by impact measurement & evaluation of services to ensure the highest quality services possible.

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We seek to raise the profile of our work with existing & new stakeholders, bringing our influence to bear in shaping policy & practice to affect positive change for all our families.



 /TinyLifecharity  @tinylifecharity

## **TinyLife**

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Tiny Life is registered as a company limited by guarantee in N.Ireland

