Spring/Summer 2025

# talking sense

**Special 70th anniversary edition!**

- **Our story:** Two families, one mission
- **70 years of moments and milestones**
- **From 1983 to now:** Supporting Paul at every stage of life


NEWSLETTER... November 1981. Editor: Gabriel Firth

Holiday in Southport

Talking Sense. The National Deaf-Blind and Rubella Association

National Plan

Weekend Away

Members News

Touching Talk

Season's Greetings to all our friends and supporters!

NEWSLETTER... NEWSLETTER... NEWSLETTER

Talking Sense. The National Deaf-Blind and Rubella Association

Holidays

MMR

Tadoma

Weekend Away

Season's Greetings to all our readers

Sense. The eyes and ears of deaf-blind people.

Volume 40 No. 4 Winter 1994

Talking Sense. The magazine of Sense, the National Deafblind and Rubella Association

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Practicalities: from presents to places to go. Pages 12-22

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Talking Sense. The magazine of Sense, the National Deafblind and Rubella Association

Parliament – Sense hosts a reception at the House of Commons

In Depth – our feature section in this issue demonstrates Sense's commitment to good practice. pages 9-27

the magazine about deafblindness

talking sense. Summer 2011

Fighting for the future of social care

talking sense

Sense celebrates its 65th birthday!

## Marking 70 life-changing years.

sense | 70 years

# In this issue

## Say hello!

We’d love to hear from you. We’re happy to consider articles for publication but we reserve the right to edit material where necessary. Get in touch if you have news, views or stories you would like to share. **If you would like Talking Sense in an email format, please email** **supporterservices@sense.org.uk** Please note that the views expressed in Talking Sense are not necessarily those of Sense.

talking sense

**Volume 71 No 1 Spring/Summer 2025**
ISSN 13674604
Talking Sense online: **sense.org.uk/blog**
Tel: **0300 330 9257**
Email: **supporterservices@sense.org.uk**
Editor: **Lydia Willetts**
Design: **tenfathoms.co.uk**

Sense
101 Pentonville Road,
London N1 9LG

Published by Sense. Sense is a registered charity number 289868. Registered as a company limited by guarantee in England and Wales number 01825301.

# A letter from your editor

**You might have noticed that this issue of Talking Sense looks a little different to normal. At Sense, this year is a little different too. This year marks our 70th anniversary, a chance to reflect on seven decades of working together to support disabled people and their families. To mark this significant year, we're taking inspiration from past issues of Talking Sense.**

In April 1955, Peggy Freeman, mother of Bunty, a child born deafblind, wrote a newsletter to a small group of other parents with deafblind children. These parents had no support and nowhere to turn.

This newsletter not only marked the start of a series of newsletters which became a vital lifeline for parents, but also marked the true beginnings of Sense. In later years, these newsletters evolved into 'Talking Sense'.

Although a lot has changed since Peggy wrote that first letter to families, a lot has remained the same. Seventy years on, disabled people with complex needs continue to face barriers to taking part in life. Families continue to struggle to navigate social care systems. Carers continue to go without essential respite. Seventy years on, Sense continues to unite with them, thanks to the ongoing support of people like you.

We're proud to continue the legacy of Sense's early pioneers, including our founders, Peggy Freeman and Margaret Brock, and the families that rallied together to raise awareness, educate and support each other. Their values of inclusivity, innovation, personalised support, connection, boldness and determination still shape our work today. You can read more about our founders and their remarkable journey on page four. They started Sense as a support network for families with deafblind children, and so it feels fitting that we mark our 70th year by launching a campaign to secure better care for disabled children. Find out more about this on page 11.

You can also read about another incredible mother, Christine, whose son Paul has been supported by Sense since he was three years old. He continues to receive invaluable support from our services today, 42 years on.

On page nine, Steve, who leads our safeguarding team, talks about our unique approach to supporting disabled people, and how person-centred care is, and always will be, our priority.

As we mark this huge milestone in our history, we know that there is still crucial work to be done. The government's recent announcement to change disability benefits is a stark reminder of this. If these plans go ahead, life will become harder for disabled people at a time when it already costs more to simply live.

In this issue you'll also find five ways that you can get involved to ensure we can continue our work to create a world where disabled people are connected and included, no matter what.

L. Willetts

Lydia Willetts, editor

## Visit our 70th anniversary hub and share your stories

Head over to our website to discover more about the history of Sense, the people we've supported past and present, our plans for the future and how you can mark this milestone year. If you have a story to share about your journey with Sense over the past 70 years, please let us know. We'd love to hear from you at 70th.stories@sense.org.uk

**sense.org.uk/70**

# A message from James, chief executive of Sense

**In April 1955, Peggy Freeman wrote the first Sense newsletter, describing it as her ‘first effort’ at bringing the families of deafblind children together. It’s therefore a real honour, 70 years later, to have my own ‘first effort’ as Sense’s new chief executive.**

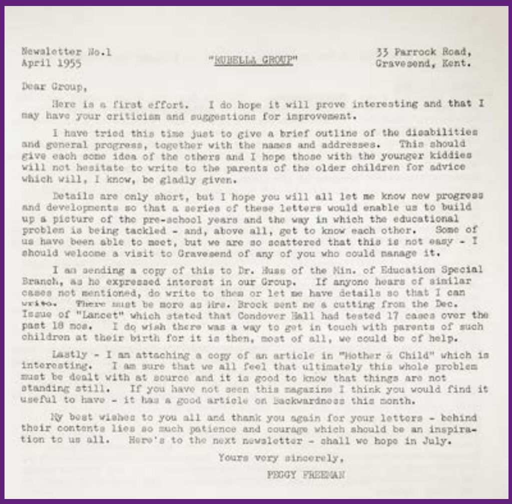
Since joining Sense in February, I’ve travelled the country visiting services. I’ve met with the people we support, their families, volunteers, and staff. The fantastic work I saw overwhelmed me and I feel really proud to be here.

I join Sense at a time of huge importance, our 70th year. It all began with two mothers who had nowhere to turn to when their children, Bunty and Christopher, were born deafblind. As they reached out to other families, their support network grew. From that small group, we have grown into the leading charity we are today, supporting disabled people at every stage of their lives.

As we mark seven life-changing decades, we look back at all we’ve achieved with pride. This issue of Talking Sense includes a timeline of our history so you can see how far we’ve come. We’ve expanded our residential services, opened specialist education provisions and launched groundbreaking arts, sports and wellbeing programmes. We’ve provided disabled people with life enriching holiday experiences, supported families to connect with their children and, more recently, motivated over 80,000 people to campaign for more support for disabled people during the cost of living crisis. But we know there is still more work to do.

I was recently shown a quote from an old Talking Sense magazine. In April 1965, Peggy wrote:

**“Although we have made considerable progress … we cannot afford to be complacent - our ‘way’ is long, there are still many battles to be won, but we have every reason to be in good spirits.”**



Newsletter No.1
April 1955

"RUBELLA GROUP"

33 Parrock Road,
Gravesend, Kent.

Dear Group,

Here is a first effort. I do hope it will prove interesting and that I may have your criticism and suggestions for improvement.

I have tried this time just to give a brief outline of the disabilities and general progress, together with the names and addresses. This should give each some idea of the others and I hope those with the younger kiddies will not hesitate to write to the parents of the older children for advice which will, I know, be gladly given.

Details are only short, but I hope you will all let me know new progress and developments so that a series of these letters would enable us to build up a picture of the pre-school years and the way in which the educational problem is being tackled - and, above all, get to know each other. Some of us have been able to meet, but we are so scattered that this is not easy - I should welcome a visit to Gravesend of any of you who could manage it.

I am sending a copy of this to Dr. Huss of the Min. of Education Special Branch, as he expressed interest in our Group. If anyone hears of similar cases not mentioned, do write to them or let me have details so that I can write. There must be more as Mrs. Brock sent me a cutting from the Dec. Issue of "Lancet" which stated that Condover Hall had tested 17 cases over the past 18 mos. I do wish there was a way to get in touch with parents of such children at their birth for it is then, most of all, we could be of help.

Lastly - I am attaching a copy of an article in "Mother & Child" which is interesting. I am sure that we all feel that ultimately this whole problem must be dealt with at source and it is good to know that things are not standing still. If you have not seen this magazine I think you would find it useful to have - it has a good article on Backwardness this month.

My best wishes to you all and thank you again for your letters - behind their contents lies so much patience and courage which should be an inspiration to us all. Here's to the next newsletter - shall we hope in July.

Yours very sincerely,

PEGGY FREEMAN

Described by Peggy Freeman as her ‘first effort’, the first Sense newsletter was sent to parents of deafblind children in April 1955 and marks the true beginning of Sense. The newsletter went on to become the Talking Sense that we see today.

Whilst it’s important we celebrate all we’ve achieved together, far too many disabled people still aren’t getting the care they need, the education they deserve, the respite their families rely on,or the financial support required just to get by. As a disabled person leading a disability charity, I’m determined that we do everything we can to support those facing these extreme challenges.

With your continued support, we can work towards achieving long-term change. I want to thank you for uniting with disabled people with complex needs in this significant year, and into the future.

I know I speak for everyone at Sense when I say we promise to do everything that we can to continue to grow the legacy of the inspirational women and families that started Sense, with nothing but £2.25 between them and sheer determination to break the barriers their children faced.

Thank you.

James Watson-O’Neill

# Our story: Two families, one mission


Margaret Brock


Peggy Freeman

It all began with two mothers – Peggy Freeman and Margaret Brock – who saw limitless potential in their deafblind children, despite the barriers they faced.

In 1946, Margaret Brock contracted rubella during pregnancy and, in 1951, Peggy Freeman faced the same. As a result, both of their children, Bunty and Christopher, were born deafblind. The two mothers didn't know who to turn to, and no one knew how to help them.

With no support available, they decided to take matters into their own hands. They knew there must be other families in need of support. Through contacts and letters, they soon discovered that there were and their group grew into ten founder families known as 'The Rubella Group'. The group focused on what Bunty, Christopher and other deafblind children could achieve, rather than what they couldn't.


Christopher and Margaret Brock


Bunty Freeman

> **"Together they conquer the darkness and silence that is their children's world."**
> Peggy Freeman's article in 'Woman Magazine', 1955

> **"When Peggy and I first met…we could not possibly have foreseen how our search for other rubella parents would develop."**
> Margaret Brock

Through sheer determination, they proved to the world that, with the right support at the right time, their children could learn, communicate and develop.

After registering as a charity in 1961, The Rubella Group would go on to become Sense, as we're still known today.

From their humble beginnings, Peggy and Margaret went on to pioneer revolutionary work in specialised support for children and young people. Their commitment to breaking down barriers for disabled people drove landmark changes in education, health and social care.

Both Peggy and Margaret were awarded MBEs for their incredible work.

Today, their legacy lives on. The values that Peggy and Margaret embodied – inclusivity, innovation, personalised support, connection, boldness and determination – have shaped and are still embedded in our work today.

# 70 years

## of moments and milestones

### 1946

Margaret Brock contracts rubella during pregnancy. Her son, Christopher, is born deafblind as a result.

### 1951

Peggy Freeman faces the same and her daughter, Bunty, is also born deafblind.

### 1954

Peggy and Margaret first meet.

### 1955

The start of Sense. Peggy sends the first Sense newsletter to other parents of deafblind children.

### 1955

The group grows via newsletters and now includes 12 families known as The Rubella Group.

### 1961

The Rubella Group officially register as a charity.

### 1970

The Education Act is a breakthrough moment after years of campaigning.

### 1971

Support is expanded to include deafblind young people and adults.

### 1974

The first ever Sense holiday takes place.

## 1980

Manor House opens. It is the first of its kind in the UK, providing housing, training and education for disabled adults.

## 1980

Sense's first family centre in Ealing opens.

## 1981

The Rubella Group becomes known as 'Sense'.

## 1983

Support extends to people with acquired deafblindness, including those with Usher syndrome.

## 1989

Her Royal Highness The Princess Royal becomes Sense's patron.

## 1994

Sense International is set up, extending our reach to multiple countries around the world.

## 1995

Protests by disabled people lead to the landmark introduction of the Disability Discrimination Act.

## 2001

As a result of Sense's 'Yes to Access' campaign, the government publishes its first deafblind guidance.

## 2010

The Equality Act is passed by Parliament days before the general election. It outlaws direct or indirect discrimination and harassment which includes disability.

## 2013

Sense launches pioneering arts, sports and wellbeing programmes.

## 2017

Sense TouchBase Pears opens in Birmingham, combining specialist provision for disabled people with community activities.

## 2024

Over 25,000 campaigners sign our plan for change petition.

## 2025

Sense marks its 70th anniversary.

# From 1983 to now:

# Supporting Paul at every stage of life

**Sense has been a part of Paul and Christine's lives since he was just three years old. He was born with congenital rubella syndrome, causing both hearing and sight loss. Here, Christine talks about the invaluable impact Sense has had on her family during the 40 years that we've supported Paul.**

When Paul was born at home in Southend-on-Sea, he didn't look well and had to be rushed to the hospital. For the next 48 hours, we couldn't see him. During that time, we decided to name him Paul, after Paul McCartney. When we were finally allowed to visit, we learned that he had congenital rubella syndrome.

Paul has been profoundly deaf from birth and has lost his vision over time. Learning how to communicate with him has been challenging. He experienced poor health throughout his childhood too, and at just three months old, he had to undergo open-heart surgery.

I took home a child from hospital that couldn't see me, couldn't hear me and couldn't feed. There was no support, and I had no-one to turn to.

When Paul was around three years old, I read about Norman Brown, another parent of a deafblind child, who worked for Sense. Through him, we connected with the Sense Family Centre in Ealing and started attending a support group with other families with deafblind children. Little did we know that this was the start of an amazing life-long journey with Sense. I still speak to quite a few of those families today.

Meeting these other parents was life-changing. We could finally talk to people who truly understood what we were going through. We had a weekend away together once a year, and we could connect with other parents about their children. We'd talk about anything and everything – they understood like no one else!

In 1983, Paul and his brother Mark were featured in a Sunday Times article that highlighted Sense's work. Paul was even on the cover! This helped raise awareness and funds for the specialist school he attended in Walthamstow. The teachers there were trained by Sense to provide expert support.

Even after Paul left school, Sense continued to be there for us. They helped him live independently, first in Birmingham and then back in Walthamstow, where he's been for over 20 years. I live in Essex now and Sense staff support Paul to visit me every month so we can have meals together.

Sense has been there for all stages of Paul's development. They've taken him on holiday, educated him and kept him alive. They've been a huge part of our lives. I couldn't be more grateful.

> **Sense has been there for all stages of Paul's development… They've been a huge part of our lives. I couldn't be more grateful.**
>
> Christine, Paul's mother

# 70 years of trailblazing

## support for disabled people

**Over the last 70 years, Sense has grown from a small group of families supporting each other, to a national charity reaching over 30,000 people a year. We've evolved from an organisation focusing on deafblind children, to one that fights to ensure disabled people of all ages are connected and included. Though our reach has increased, our unique approach to support has remained the same.**

Steve has dedicated over four decades of his life to Sense. He started as a holiday volunteer in 1982 before joining our social care team. Over the last 43 years, Steve has seen Sense reach many milestones, including growing our services throughout the West Midlands. He's also played a crucial role in our pioneering approach to safeguarding.

Here we hear from Steve about championing person-centred care.

"Sense has always been forward-thinking. When Manor House, our first residential service, opened in the 1980's, we encouraged the people we supported to learn new independent living skills like cooking – it was quite trailblazing back then.

"We've never restricted the people we support. We've also always believed in empowering disabled people to take risks and try new experiences safely. That's a core part of what makes our services and care so unique. It's an ethos we firmly believe in to this day. I once took a group caving in Wales, and when one young person felt nervous, I went first, signing with them the whole way to keep them calm.

> **"The aim here…is to draw out those talents and abilities often overlooked in children who cannot see, hear or speak."**
> Early Manor House guide

> **"Our approach has never been to restrict the people we support."**
> Steve Kiekopf - head of corporate assurance and safeguarding

"Person-centred care has been central to Sense since the very beginning. We used to use personal symbols and objects of reference, which has evolved into a key part of our work. Total communication has always been a focus for us.

"Throughout my time here, there has always been new opportunities and challenges. We've always been encouraged to find new ways of supporting the people in our services and to get them involved."

At Sense, we celebrate what people can achieve – whether that's making a cup of tea independently or reaching new heights on a rock-climbing wall. This ethos has been part of us since Sense was founded 70 years ago by families who proved that, with the right support, their children could thrive. We're proud to continue that legacy in everything we do.

**Steve (bottom right), in Perth, Australia with a group from Sense at the Deafblind International Conference**

# Giving back to Sense after four decades of support

**Empowering the people we support to try new things, discover hobbies they love, and make the most of new opportunities has always been important to us. For Susan, who we've supported for over 40 years, her passion for architecture and design led her to an incredible opportunity to be involved in a pioneering Sense project.**

Susan has been receiving personalised support from Sense since she was a teenager. She's now 60, and lives in a Sense home in Birmingham.

Born deafblind, Susan has always been passionate about architecture and design. In 2014, Sense began planning a pioneering new community centre called Sense TouchBase Pears in Birmingham. This accessible hub would provide specialised services for disabled people, as well as inclusive events for the whole community. Susan jumped at the chance to get involved, moving from Lincolnshire to be closer to the project.

Susan went to site visits, planning sessions and meetings, and met with Sense staff, volunteers, businesses and parliamentarians to get them excited about the development. She also completed a work placement with the project's architects, using her lived experience to consult on design and accessibility features. Many of Susan's ideas were incorporated into the final building, like ensuring contrasting colours were used to highlight the doors of accessible bathrooms, making them more visible to people with visual impairments.

In 2016, Susan performed for Sense's patron, HRH The Princess Royal, to raise awareness of Sense TouchBase Pears before it opened. Later that year, she was named "Deafblind Person of the Year" at the Sense Awards for her contributions.

Today, Susan continues to explore her passion for architecture, venturing to cities like Rome, Germany, and Croatia with Sense's support.

At Sense, we're experts at providing support, but we also know the people we support are experts too. With the help of Susan, we built an accessible community centre that brings disabled people and the wider public together, now and in the future.

# Better care for disabled children

**Over Sense's 70 year history, our support has expanded to reach disabled people at every stage of life, but our vital work with children and families has been at the heart of what we do from the very beginning. Now, as move into our 70th year, we are turning our campaigning focus to the children and families across the UK who are not receiving the support they need and are entitled to.**

Backed by new research and a report that we're taking to government, our findings reveal a system that is failing those who need it most.

Families of disabled children are forced to navigate a complex, fragmented system to try and find the support their children desperately need. They face repeated assessments, causing unnecessary delays to essential care, adding immense stress and leaving too many children without the support required to reach their full potential. Even when support is approved, more than half of parents are struggling to find local services that adequately meet their child's needs.

Alarmingly, many families fear seeking help, believing the system prioritises cost-cutting over care.

The toll on parents is profound. Many provide round-the-clock care without a break, leading to exhaustion, isolation, and an overwhelming fear that their children are missing out on vital opportunities to grow, learn, and thrive.

To change this we need stronger children's social care laws, designed for and with disabled children. We're calling on the government to set out a national threshold for support, so that no more disabled children fall through the cracks. This must be underpinned by long-term funding for the specialist services disabled children need and more disability training for all professionals.

**61%**

**of families feel local authority decisions are driven by budget concerns, rather than the wellbeing of disabled children.**

1.7 million disabled children in the UK deserve a social care system that works for them – a system that prioritises inclusion, opportunity, and the support every child has the right to receive.

## We want to hear from you

Your voice matters. If you are a parent or caregiver of a disabled child, we invite you to share your experiences of navigating the care system. Your insights will play a crucial role in shaping our campaign and informing the actions we take in the future.

**Share your story with us by:**
**Visiting: sense.org.uk/care-campaign**
**Emailing: campaigns@sense.org.uk**

# There's never been a more important time to support Sense

**Our 70th anniversary gives us the opportunity to reflect on our past, but also to look ahead to the future. As we mark this important milestone in our history, we recognise that there is still work to be done.**

Regardless of how long it takes, how many barriers we need to overcome or how hard we have to fight, we'll stop at nothing to create a world where disabled people are connected and included, no matter what. But to do that, we need your help.

## Here are 5 ways that you can support Sense in our 70th year, and beyond:

### 1 Donate

Your vital support could help to create moments of joy and connection for disabled people and their families.

### 2 Fundraise

Challenge yourself to raise vital funds by taking part in one of our events, or fundraise your own way.

### 3 Volunteer

Support your local community while learning new skills that will help you grow both personally and professionally.

### 4 Shop with us

Drop off a bag of unwanted items or grab yourself a bargain at one of our Sense charity shops.

### 5 Discover

Join over 80,000 people who already receive our weekly email, filled with inspiring stories, tips on how to be more inclusive and ways you can drive change.

Scan this QR code to find out more, or visit **sense.org.uk/get-involved**