

# **Value of Voice**

**Auto-immune  
System Conditions  
Diabetes Type 1**

**Rheumatoid  
Arthritis**

# Contents

Statutory Requirements of a Healthwatch	2
How do we capture insights	2
What are autoimmune conditions?	2
Type 1 Diabetes	3
Rheumatoid Arthritis	3
The impact of Type 1 Diabetes on Daily life	4-5
The impact of Rheumatoid Arthritis on Daily life	6-7
Experiences of Health and Social Care Services	7
What has worked well	8
What hasn't worked well	8
What could be improved	9
Recommendations	9
Conclusion	10

## STATUTORY REQUIREMENTS of a LOCAL HEALTHWATCH

1. To obtain the views of Luton residents on health and care service, to help shape the delivery and improve the quality of designing and commissioning services.
2. To make recommendations to service providers and commissioners in developing, designing, shaping, and improving the quality-of-service delivery
3. To support the involvement of Luton residents in the designing and commissioning of local services
4. Provide information and advice to inform Luton residents on choices available to them.
5. To escalate findings to local commissioners, providers and nationally to Healthwatch England along with recommendations for service change.

## Healthwatch Luton Autoimmune Diseases Case Study

### How do we capture insights?

Healthwatch Luton is the independent consumer champion for health and social care. Our role is to gather and represent the views of local people, ensuring that lived experiences help shape and improve services. We feed these insights into both local and national decision-making, so that your voice influences the way care is planned and delivered.

### What are autoimmune conditions?

Autoimmune conditions are health conditions that happen when your immune system attacks the body instead of defending it from viruses and bacteria. Rheumatoid arthritis and Type 1 diabetes are both autoimmune conditions. Autoimmune diseases are chronic conditions, which you will have for life. It is not known what causes autoimmune diseases, but there are some risk factors. Women are more likely to have autoimmune conditions. Having one autoimmune disease can increase the odds of developing another one. [Smoking](#) and using other types of tobacco can cause many health issues, including potentially triggering autoimmune diseases. Tina has two autoimmune diseases, type 1 diabetes and rheumatoid arthritis.

## Type 1 Diabetes

Type 1 diabetes is an autoimmune condition in which the immune system mistakenly attacks the cells in the body. Unlike some health conditions, it cannot be prevented.

According to the NHS, key facts about type 1 diabetes include:

- *It is a condition where the body cannot produce the hormone insulin.*
- *Insulin helps the body use glucose (sugar) for energy. Without insulin, glucose builds up in the blood, leading to high blood sugar levels.*
- *People with type 1 diabetes need to take insulin every day to manage their blood glucose.*
- *Although it often develops in children and young adults, type 1 diabetes can occur at any age.*

## Rheumatoid Arthritis

Rheumatoid arthritis is another autoimmune condition, in which the immune system attacks the cells that line the joints, causing swelling, stiffness, and pain.

The NHS describes rheumatoid arthritis as a long-term condition that:

- *Causes pain, swelling, and stiffness in the joints, particularly in the hands, feet, and wrists.*
- *Can involve flare-ups – unpredictable periods when symptoms worsen.*
- *With treatment, the number and severity of flare-ups can be reduced, helping to prevent long-term joint damage.*
- *May also cause symptoms beyond the joints, such as fatigue and weight loss.*

The exact cause of rheumatoid arthritis is not fully understood, but several risk factors have been identified. You may be at higher risk if:

- *You are a woman.*
- *You have a family history of rheumatoid arthritis.*
- *You smoke.*

## The impact of Type 1 Diabetes on Daily Life

For Tina, living with type 1 diabetes has been a daily challenge since her diagnosis 29 years ago. At the time, she was caring for her six-month-old baby, which made learning to manage the condition even more demanding.

From the beginning, Tina had to test her blood glucose up to eight times a day by pricking her finger. She also learned how to inject insulin, how much insulin was needed, and how to recognise and respond to hypoglycaemia ("hypos") – episodes of low blood glucose that can cause dizziness, sweating, or shaking. Tina always keeps jelly babies with her to treat hypos quickly when they occur.

As treatments evolved, Tina's care routine changed. After 10 years, she moved from fixed insulin doses to adjusting her injections according to the carbohydrates she ate, which meant learning to count carbohydrates carefully. This made everyday activities, such as food shopping, more time-consuming as she had to check sugar content in everything she bought.

Type 1 diabetes has also affected practical aspects of Tina's life, such as driving. She had to notify the DVLA about her condition and use of insulin. While she was not stopped from driving, she must continue to demonstrate that she can manage hypos safely in order to keep her licence.

Despite the constant monitoring, injections, and adjustments, Tina has built the knowledge and resilience needed to live with type 1 diabetes while balancing work, family, and everyday life.

## Using technology to manage Diabetes

Tina does not experience symptoms or warnings when her blood glucose levels drop. Her consultant therefore recommended continuous glucose monitoring (CGM) and successfully applied for NHS funding. Tina now uses a hybrid closed loop system – an insulin pump that communicates with her G7 sensor to automatically manage her blood glucose.

With this system, Tina enters the carbohydrate content of her meals, and the pump calculates and delivers the required insulin dose. The technology has made managing diabetes more accurate and less stressful.

There are, however, important practical requirements. Tina must:

- *Replace her G7 sensor every 10 days.*
- *Change the pump cannula every 3 days, which she plans carefully so that it is done at home.*
- *Store supplies delivered every 3 months, including pump equipment and sensors.*

Although provided by the NHS, these supplies are not available on prescription. Tina also keeps insulin cartridges, needles, and pens in case the pump fails, and she takes these backups with her when travelling. The pump must be charged daily for at least 15 minutes to ensure it maintains full battery life.

While this technology requires organisation and planning, it provides Tina with greater stability and safety in managing her diabetes, particularly in reducing the risks associated with unrecognised low blood glucose levels.

## **Support Systems**

Tina's family have played an important role in supporting her to manage diabetes over the years, helping her come to terms with this long-term condition. Simple actions such as reminding her to check her blood glucose or asking whether she needs something sweet have provided reassurance and encouragement.

For clinical support, Tina has a contact telephone number for her diabetes nurse. However, it can take up to three days for calls to be returned, which can be stressful when an issue requires a quicker response.

With the introduction of continuous glucose monitoring and pump technology, Tina now has access to additional support services. She can contact the Air Liquide Technical Support Team 24 hours a day, seven days a week, for assistance with her insulin pump. The team are friendly and helpful, although they make clear that they cannot provide medical advice and will direct patients back to their diabetes team for clinical concerns.

For her G7 sensor, Tina can contact Dexcom from Monday to Friday, 7am to 6pm, and on weekends from 8am to 4.30pm. They provide technical support for issues with the sensor or app, such as reinstalling the system. If a sensor fails, a replacement is sent within five days.

## **The impact of Rheumatoid arthritis on daily life**

Tina was diagnosed with rheumatoid arthritis after being rushed to hospital when her hip seized and she became stuck in a chair for two hours. Fluid was removed from her right hip, and she remained in hospital for five days. At the time, staff were reluctant to discharge her in case she had stairs to climb at home, but fortunately she was living in a ground floor flat.

Since then, rheumatoid arthritis has had a significant impact on Tina's daily life. Symptoms are unpredictable, and she never knows how she will feel from one day to the next. She may go to bed without pain, only to wake up unable to move. Flare-ups arrive without warning, forcing Tina to plan her days carefully around her level of pain. At times, she has had to cancel plans with friends or family.

Long journeys require particular preparation, as Tina must stop every two hours to stretch before continuing. At home, she has adapted her environment to make daily activities more manageable. She uses a walk-in shower with lever taps instead of a bath, and has installed a stair lift.

During flare-ups, Tina relies on crutches to walk, which help manage the pain but sometimes lead to shoulder strain lasting several days. These adjustments, while necessary, reflect the ongoing and unpredictable impact of rheumatoid arthritis on her life.

Just as with her diabetes, Tina must plan carefully, adapt her routines, and remain resilient in the face of daily challenges posed by rheumatoid arthritis.

## **Support for Rheumatoid arthritis**

Tina can contact the rheumatology nurse for advice, but it may take up to three days to receive a call back. This delay can be difficult, as she usually seeks help when she has already been in pain for several days, meaning her symptoms may have lasted a week or more before she receives professional support.

Alongside clinical input, Tina's family play an important role in helping her cope with the day-to-day challenges of rheumatoid arthritis. Their encouragement and practical assistance, as with her diabetes, remain her most immediate and reliable form of support.

In addition to family support, people living with rheumatoid arthritis are often supported by a wider healthcare team. This may include consultants, physiotherapists and occupational therapists, who can advise on managing mobility, adapting the home, and protecting joints. Charities such as *Versus Arthritis* also provide valuable peer support, information, and practical advice.

Although Tina has made adaptations in her home and uses equipment such as crutches and a stair lift, quicker and more responsive support from clinical teams would make living with rheumatoid arthritis more manageable.

## **Experiences with Health and Social Care Services**

Tina's experiences of health and social care have varied over the years. In the past, she faced challenges with delays, limited support, and the stress of managing long-term conditions largely on her own. For example, waiting up to three days for a call back from a nurse – whether for diabetes or rheumatoid arthritis – often meant enduring pain or uncertainty for a week or more before receiving professional guidance.

At the same time, Tina has also benefited from positive developments. The successful application for NHS funding for continuous glucose monitoring and a hybrid closed loop system has transformed the way she manages her diabetes. The support provided by technical helplines for her insulin pump and G7 sensor has given her reassurance that help is available when equipment fails. These improvements have made her feel more supported and safer.

In social care, Tina has had to adapt her home environment with equipment such as a stair lift and walk-in shower. While these adaptations have been essential, she has relied heavily on her family to fill the gaps left by formal services. Their support has often been more immediate and reliable than the clinical care available.

Overall, Tina is happier with the care she now receives than in the past, but her experiences highlight the importance of timely responses, access to new technologies, effective pain management, and coordinated support across health and social care services. Sharing lived experiences such as Tina's helps organisations like Healthwatch Luton to ensure services reflect the needs of the people who use them.

## What has worked well

- Since moving onto the G7 sensor and insulin pump, Tina feels she has much better control of her diabetes. The system alerts her if her blood glucose is rising or falling and shows whether her levels are stable or changing. This has given her greater confidence in daily life.
- Tina has found it reassuring to have a consultant who understands the complexities of living with both type 1 diabetes and rheumatoid arthritis. For example, the consultant recognises that steroids, often prescribed for rheumatoid arthritis, cannot be used in Tina's case as they interfere with diabetes management.
- The consultant has also shown sensitivity to Tina's daily life. An assessment question once asked whether she could lift a saucepan containing four potatoes. Knowing that Tina cooks regularly for her family, the consultant adapted the question to reflect a more realistic task. This made Tina feel her circumstances were recognised and respected.

## What hasn't worked well

- Pain management has been a particular challenge. Tina explained that the only medication that truly eases her pain is morphine or codeine. However, these are not prescribed for her, leaving her reliant on ibuprofen, which does not adequately control her symptoms.
- When her consultant first applied for funding for an insulin pump, the request was refused because she had occasionally missed injections due to the impact of rheumatoid arthritis on her hands. It took five years before the NHS approved the funding.
- Tina's appointment with Air Liquide to activate the CGM system on her insulin pump lasted only one hour and was delivered via Teams. She felt this did not allow enough time for questions, and when she contacted her diabetes nurse for support, they were unable to help as they had not been trained on the system.
- Tina has also faced difficulties with sharps disposal. Although instructed by her consultant to return her purple sharps box to the hospital pharmacy, she was questioned about who prescribed it and redirected to her GP practice or local pharmacy, neither of which would accept it. This lack of clarity created additional stress and inconvenience.

## What could be improved

- A consistent and reliable system for sharps box disposal would remove unnecessary stress and make it easier for people like Tina to manage her condition safely. Luton Borough Council briefly provided this service after Healthwatch Luton's involvement, but it was discontinued after two years.
- Diabetes nurses should be trained on the CGM and pump system before patients are placed on it, so that they can provide meaningful support.
- The time it takes for diabetes nurses to return calls should be reduced. At present, call backs can take up to three days.
- More regular review appointments would help patients feel supported and monitored. Tina was told this could not be offered due to staffing shortages, but she believes three-monthly reviews would make a meaningful difference.

## Recommendations

From Tina's experiences, several opportunities for improvement in health and social care can be identified:

- **Quicker response times** – reduce the waiting period for call-backs from diabetes and rheumatology nurses so that support is available when it is most needed.
- **Consistent sharps disposal services** – establish a clear and reliable system for disposing of sharps boxes locally, removing unnecessary stress for patients.
- **Training for clinical teams** – ensure diabetes nurses and other frontline staff are fully trained on new technologies such as continuous glucose monitoring and insulin pumps before patients are placed on these systems.
- **Regular review appointments** – provide routine follow-up appointments, for example every three months, to monitor progress and offer reassurance to patients with long-term conditions.
- **Access to effective pain management** – review prescribing practices to ensure that people with rheumatoid arthritis receive appropriate and effective pain relief.
- **Holistic understanding of patient needs** – continue to adapt assessments and care plans to reflect real-life daily challenges, recognising the individual circumstances of each patient.

## Conclusion

Healthwatch Luton would like to thank Tina for sharing her experiences of living with type 1 diabetes and rheumatoid arthritis. Her openness in describing both the challenges and the positive changes highlights the realities of managing long-term conditions on a daily basis.

By listening to lived experiences such as Tina's, health and social care services can better understand what works well and where improvements are needed. These insights not only help shape more responsive and effective services but also ensure that other people living with similar conditions benefit from care and support that truly reflects their needs.

# healthwatch

Healthwatch Luton

Website:

<https://www.healthwatchluton.co.uk/>

Telephone: 01582817060

Email: [info@healthwatchluton.co.uk](mailto:info@healthwatchluton.co.uk)

Futures House

The Moakes