

Home Therapy Immunoglobulin

Author: Michael Duddridge, Consultant, Rejoice Sango, Specialist Nurse

Sponsor: Julie Smith, Chief Nurse

Trust Board paper E

Executive Summary

This patient story focuses upon the positive experience of home therapy delivered by Clinical Immunology. A patient shares with the Trust Board their experience of administering subcutaneous immunoglobulin replacement therapy using the new daily rapid manual push method without the use of any syringe drivers as required for traditional weekly therapy.

Patient Experience

This patient story will be shared via a video link. The main points raised are:

- Infusing at home has given the patient control over their illness and treatment plan.
- Infusing at home has greatly reduced hospital visits.
- The use of immunoglobulin replacement therapy has seen a reduction in infections and hospital admission with infection related illnesses.
- Subcutaneous immunoglobulin therapy also reduces the peaks and troughs a patient gets with intravenous immunoglobulin therapy hence helping in achieving a stable level all the while.

Immunoglobulin Replacement Therapy

Immunoglobulin replacement therapy is offered to patients with primary and secondary antibody deficiency to help reduce the number of infections they are getting. These patients have rare diseases caused by a part of the immune system being missing or not working well. Antibody deficiency is characterised by low or absent levels of immunoglobulin in the blood. Immunoglobulins are antibodies that are essential for the immune system to fight infections. Patients who lack these protective antibodies can be treated with immunoglobulin made from the blood of healthy individuals. Historically this has been given as an infusion into a vein every three weeks, usually in hospital.

Home Therapy Subcutaneous Immunoglobulin Programme

We have been treating patients with subcutaneous immunoglobulin and training them for home therapy on a Wednesday at the Leicester General Hospital for many years. We have recently introduced daily rapid manual push therapy where a portion of immunoglobulin is administered on a daily or alternate daily basis. Weekly therapy has been offered for many years but using syringe drivers to deliver the larger dose. We noted that some of the patients struggled with the syringe drivers hence the introduction of the rapid manual push method. The immunoglobulin dose is calculated according to the patient's weight and then divided into daily doses according to how much the patient can tolerate. Patients are trained in hospital for a minimum of six sessions to ensure that there are no reactions and they are happy giving their own therapy. Upon completion of training a specialist nurse will be present for the first treatment at home to help the transition to self-care. Follow up is in clinic at least every 6 months with a home visit after a year, or earlier if necessary. Hospital visits are reduced significantly as are infection risks. Importantly, home therapy also promotes expert patients with independence from the hospital and control of their life-long treatment.

Learning from Patient Experience

Our team has worked together to set the Home Therapy Service up and continue to provide an excellent service for all our patients. We have explored different options on how best to deliver training for subcutaneous immunoglobulin therapy at the same time as giving our patients the full attention they need during training. We are responding by planning to reduce unrelated activity on a Wednesday to improve dedicated training time and future patient training experience. Our team is one of the few units in the country offering rapid manual push and we plan to take it forward by

offering this service to all our patients who are suitable for home therapy and meet the criteria for training.

Conclusion

This patient story shows how home immunoglobulin replacement therapy has improved their life and this also relates to the three quarters of our patients on home therapy. Patient choice remains fundamental as different patients have different needs. All suitable patients are offered home therapy if, and when, they meet the criteria. The new daily rapid push method for home subcutaneous immunoglobulin therapy extends patient choice according to their lifestyle and working or education patterns. The flexibility of home therapy allows patients to administer their therapy at a time of their choice, not be restricted by having to attend hospital for therapy or travel for therapy. It fits in with today's working or education patterns and life activities rather than dictating a need for time off work, education or other life activities.

Input Sought

The Trust Board is asked to:

- Receive and listen to the patient's story
- Support our Home Therapy Service so that patients can enjoy Caring at its Best

For Reference

1. The following objectives were considered when preparing this report:

Safe, high quality, patient centred healthcare	Yes
Effective, integrated emergency care	Yes
Consistently meeting national access standards	Not applicable
Integrated care in partnership with others	Yes
Enhanced delivery in research, innovation & ed'	Not applicable
A caring, professional, engaged workforce	Yes
Clinically sustainable services with excellent facilities	Yes
Financially sustainable NHS organisation	Not applicable
Enabled by excellent IM&T	Not applicable

2. This matter relates to the following governance initiatives:

Organisational Risk Register	Not applicable
Board Assurance Framework	Not applicable

3. Related Patient and Public Involvement actions taken, or to be taken:

This patient story consists of feedback from a patient directly about their experience of care. In response to this feedback the Trust identifies how best practice will be disseminated across the organisation.

4. Results of any Equality Impact Assessment, relating to this matter: Not applicable

5. Scheduled date for the next paper on this topic: 3 August 2017

6. Executive Summaries should not exceed 1page. My paper does comply

7. Papers should not exceed 7 pages. My paper does comply