

LEMTRADA LINK

Use of Social Media to Enhance the Patient Experience.

Michelle Allan RN

Multiple Sclerosis Clinical Nurse Consultant
Neurosciences Department, Monash Medical Centre

INTRODUCTION

The use of social media has grown in all areas of our lives and many of our patients are now using it to interact and gain information about their disease and treatments from others who have experience of the same.

Alemtuzumab (Lemtrada) was approved in Australia on April 1st 2015. There were many questions that the patients had around Alemtuzumab, some of these were best answered by people who had already undergone treatment. Lemtrada link was developed for this purpose.

Lemtrada Link is a closed facebook group for people who are about to be treated with Alemtuzumab, or those who have already undergone treatment who are patients of two of the large Multiple Sclerosis clinics in Melbourne, Australia.

The purpose of Lemtrada link was to create a positive platform where individuals can share their own experiences, ask questions and provide support to other group members who are also on their own Alemtuzumab journey.

This poster will share the experience of Lemtrada link. Examine how it was set up, its use by patients, its successes, where and if it has been of value to the patients. It will also look at the value of social media as a health professional and whether we have been able to enhance the patient experience by using it.

BACKGROUND

- Identified need - patients had some questions that were best answered by someone who had already had treatment with Alemtuzumab.
- The first patients treated at our centre were placed in contact with Australian participants from the pivotal Alemtuzumab trials.
- They found this a valuable experience prior to having their first year of Alemtuzumab treatment.
- Discussion and thought was given to the best way to continue this support between our own cohort of Alemtuzumab patients.
- Discussed different options at length with Genzyme, patients, corporate and marketing media consultants.
- Decided that a closed/secret facebook group was the most viable option to continue this peer support.

CONCERNS & SETUP

- There were some concerns and questions about using social media around privacy. Privacy for the patients and privacy for the Health professional moderating the group. Would concerns around this impact patient involvement? How do we maintain professionalism, boundaries and privacy as a part of this patient focused group?
- There were also concerns raised about the advice given in social media groups similar to this. How do you reduce/stop the circulation of incorrect information, advice that conflicts with the Consumer Medicine Information(CMI) and advice that does not consider individual circumstances? The Multiple Sclerosis Nurse Consultant being involved and therefore able to view, moderate, advise and correct any misinformation was an option. Being there as a resource in the background.
- Would patients join in and think that it was a valuable resource for them? Would it be seen as a reputable source of support? What if they were not involved in using social media, is it fair to exclude them? Is there another way to do this?
- Discussed these concerns at length with the marketing and media consultants that we had been in communication with.
- Had informal discussions with the current patients who had been treated with Alemtuzumab or those who were about to be treated. Discussed their interest and if they could see value in this peer support and if they would like to be involved. What concerns did they have?
- Initial feedback was positive, so in August 2015 the group was launched. To cover some of the privacy concerns it was made a secret group. This means it is not searchable.
- Only members can see that it exists and joining it requires an invitation from the group administrators.
- Group administrators were the Multiple Sclerosis Nurse Consultant, and a member who works in marketing/ web design and who had also been treated with Alemtuzumab.

EVALUATION & UPTAKE

- Approximately 80% of eligible patients have joined the group. Of those who didn't the most common reason was that they were not active on social media. (Figure 1)
- Of those that joined 50% have initiated a post. These have most commonly involved asking a question or sharing their experience and support with the other members. (Figure1)
- Of all members 90% have been active and made contribution at some point since they have joined. (Figure 1)
- The most common discussion points have been questions around what to expect, sharing experiences during infusion week, post infusion and general peer support.
- It has also been a good way for group communication from the Multiple Sclerosis Nurse Consultant, for example answering questions around Listeria free diet.
- The members have enjoyed the interaction and connection that Lemtrada Link has provided them (Figure 3).
- Some have organised to meet up, they have all supported each other online during their treatment week. Many have had treatment together and then been able to stay connected afterwards and continue the support online and in person.

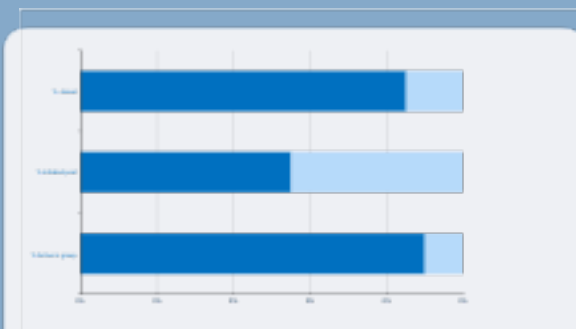


Figure 1. Evaluation & uptake

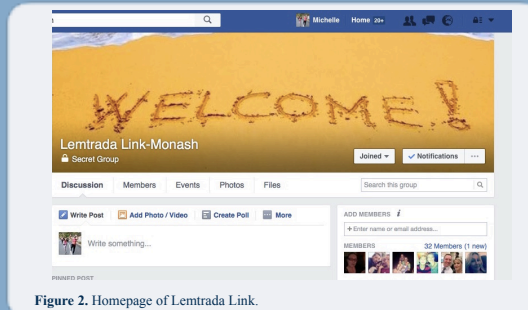


Figure 2. Homepage of Lemtrada Link.



Figure 3. Comments from members

CONCLUSIONS

- The use of social media continues to grow. Our patients are using different forms of social media to stay informed and gain support around their disease and treatments.
- Lemtrada Link has been a successful exercise and the members have gained information and peer support in an easy to access way. They have found a real bond through their common experiences. Some members had never met anyone with Multiple Sclerosis before.
- After some initial concerns around privacy and using social media, there are available security settings which have allowed the protection of members privacy.
- The Nurse Consultant being a member has also added value and allowed more options for communication between the health professional and this patient group which has been of benefit to both. This will be explored more in another poster.

The use of social media in health care can enhance the patient experience. Research the different options, respect all parties' concerns and it can improve the support available to patients.

Interaction with other patients going through similar experiences can help reduce feelings of isolation. Many patients are now part of social media groups and gain information from other members. This may not always be the correct information, taking into account a person's individual circumstances. So besides peer support, one of the real benefits found here was in the Health professional involvement and the value of local, small groups. This allowed questions and misconceptions to be cleared up quickly and has been beneficial for both parties. It has helped improve patient care, experience and outcomes.