

MASCIP Shared Learning event Conference Report

Wednesday 6th March 2019



1. Introduction

Following two previous successful MASCIP Shared Learning Events in 2016 and 2017 a need for a third event had been expressed. After initial discussions with MASCIP it was identified that they were keen to support another event and Spinal Injury Centres (SIC) had expressed genuine interest in attending a follow up from the 2017 event. There had been some significant developments within Patient Education since the last event in 2017 and it was felt that it was a good time to invite people back to update on the current projects and individual centre activity. With this in mind an event was scheduled for 6th March 2019.

2. Planning

Due to the long distances that delegates were travelling, the location of the event was crucial, in addition there had to be excellent facilities for disabled people. After some research the Radisson Blu near to East Midlands Airport was booked. Its close vicinity to the M1 and the Airport made it a good choice for travellers and there were good facilities for disabled people. In addition, the hotel was willing to reserve all their wheelchair accessible bedrooms and there was plenty of onsite parking. Once the date and location had been agreed, 'save the date' information was sent out in November 2018 to all SIC's, Patient Education Administrators/Advisors (PEAs) and our partners, Back Up and SIA. The Event objectives were agreed with MASCIP and speakers/presenters were approached and booked. During this time Aspire was also able to secure sponsorship for the event from Coloplast.

Invitations and event application forms were sent in January 2019 and places filled up very quickly; places were limited to a maximum of 35 delegates and were offered free of charge, including overnight accommodation for those that were travelling long distances, if requested.

3. Agreed Conference Outcomes

- a. To share and receive information on new developments in Patient Education in SIC around the Country.
- b. To provide tools, share skills and resources that will create a smoother experience for patients going through rehabilitation and beyond.
- c. To receive updates and presentations from research and evaluation projects that are examining patient experiences and benefits of Patient Education pre and post discharge.
- d. To examine the provision of accessible, appropriate and timely information and explore solutions.
- e. To identify barriers and solutions for the provision of peer involvement within available resources.

4. On the Day

The day was designed to have a fairly relaxed start as organisers were conscious of the distance that some delegates had to travel. However, on reflection a slightly earlier start and later finish would have provided more time for group discussion and sharing of information. The programme was designed to provide a variation of different types of delivery and interaction, but the focus of the day was about ensuring that delegates took away as much information and made as many contacts as possible.

5. Key Points raised

5.1 Mind the Gap

Mind The Gap presentations were received with interest and enthusiasm with some Centres wanting more information. Positive results were reported from the Centres in addition to some learning, this had resulted in some tweaking into the way the projects are run. It was early days for some of the Centres but updates will be reported on later in the year. (Slides are attached for more information)

5.2 Peer support

There was a consensus that peer support was an essential element of any patient's rehabilitation. Good quality peer involvement provides a unique viewpoint that is generally not available within the clinical team and will give insight, practical information, motivation and shared learning. The lived experience shared by peers demonstrates a tangible connectivity and a unique source of support and information not found anywhere else. Delegates felt that there was more openness and trust between peers and the less formal approach made it easier to relate and gave patients a source of hope, there was also a view that from a staff point of view it makes rehabilitation real and supports the work that they do.

However, despite overwhelming support for the inclusion of peers in the rehabilitation process many delegates felt there were barriers that stopped this taking place, these included:

- a. Recruitment process (SLAs etc)
- b. Lack of structure to process
- c. Risk management
- d. Finding right person, appropriate volunteers
- e. Geography and availability of peers
- f. Appropriate training and support
- g. Being ready for the role – support
- h. Patient resistance/readiness to engage
- i. Funding
- j. Clear understanding of the peer role and description

It was felt that there were solutions to many of these but some dedicated work needed to be undertaken to establish a clear way of working that delivered an effective peer support model that could be adopted by any of the Centres.

5.3 Access to, and provision of, information

Delegates were in agreement that up to date, accurate and accessible information should be available to all patients and at present it varies dramatically from Centre to Centre. The presentation from Sian Rodger from Stanmore SCIC and the joint project with UCL sparked a lot of interest and Sian agreed to keep people informed.

To assist in developing information in Centres the following barriers were identified:

- a. Who decides what information to provide
- b. Who monitors and updates resources to maintain accuracy and relevance
- c. Meeting the different access needs of patients at any one time
- d. Funding

With the development of mainstream Smart products, i.e. Alexa, providing access to resources that are accessible to everyone is more easily and cost effectively achievable and can actively meet the needs of patients who are vented, whose first language isn't English and those with impaired dexterity. Within PE sessions a range of different formats were suggested including;

- a. Video conferencing
- b. More 1:1 sessions
- c. Self-learning
- d. Subject Themed weeks across the Centre
- e. Take PE to patients who are on bed rest if unable to attend sessions for other reasons
- f. More active group discussion

There was also discussion about examining the amount of clinical jargon within presentations with a view to reduce, simplify and explain to make the sessions less intimidating. Less formal sessions with a social vibe was felt to be a positive approach and the simple act of providing refreshments could increase attendance and create a less classroom type environment. Ensuring that patients were 'ready' to take on some of the information provided in the sessions may improve the patient experience and reduce patients being turned off by too much in-depth information too soon or being given information that they don't believe they will need, or feel is relevant at the time.

6. Action Plans

The last session of the day was about providing ideas and suggestions for taking Patient Education forward in 2019. Delegates were asked to fill in an Action Plan that would include three actions each for Aspire, MASCIP and for individuals working at the Centres and the Centres themselves. These are summarised below and will be forwarded to

delegates as a reminder for action. MASCIP and Aspire will coordinate their approach to an action plan as many of the suggestions require collaboration and shared information and resources. A more detailed plan will be circulated once available.

a. Aspire

- ◆ Explore ways of sharing information and resources between Centres i.e. central accessible information resource
- ◆ Update on current information that may affect Patient Education
- ◆ Plan and deliver a 4th shared learning event in 2020
- ◆ Provide a model/guidelines for Peer support
- ◆ Provide Patient Education Guidelines/best practice
- ◆ Circulate updated information about the App development work that Stanmore is undertaking with UCL
- ◆ Facilitate a FAQ about SCI for GP's
- ◆ Develop guidelines in partnership with MASCIP for resources and delivery for patients with learning difficulties, and other additional needs
- ◆ Facilitate more Mind the Gap work in Centres
- ◆ To work with MASCIP to explore standardising PE resources
- ◆ Continue to support and fund PE work in the Centres
- ◆ Facilitate and drive forward collaborative working between charities
- ◆ Continue to promote the types of support charities can provide within SC Centres
- ◆ Provide updates to Centres on Mind the Gap
- ◆ Provide guidelines/model for PE forums

b. MASCIP

- ◆ Better promotion of MASCIP activities
- ◆ Work with Aspire to develop Peer involvement guidelines
- ◆ Explore the standardisation of core PE programme
- ◆ Facilitate the sharing of information, resources and contacts
- ◆ Develop guidelines in partnership with Aspire for resources and delivery for patients with learning difficulties, and other additional needs
- ◆ Explore ways in which pharmacists can link between Centres and share information and experiences
- ◆ Inform Centres of new resources and developments in technology.
- ◆ Facilitate more shared learning events
- ◆ Explore the possibility of a PE working party
- ◆ Examine ways in which PE can go beyond discharge
- ◆ Support a 4th PE Shared Learning Event

c. Individuals and Centres

- ◆ Review Patient Education Programme

- ◆ Review PEA role with Aspire
- ◆ Explore introducing Mind the Gap
- ◆ Keep up to date with the Mind the Gap work
- ◆ Gather data regarding PE
- ◆ Explore resources for providing peer support
- ◆ Make sure the PE programme meets the needs of the audience
- ◆ Explore the idea of FAQs/troubleshooting for GP's to help with SCI
- ◆ Talk with other Centres about information provision with a view to reviewing current resources
- ◆ Explore ways of getting 'medication' included as an essential core part of the PE programme.
- ◆ Improve my communication – one thought, one breath
- ◆ To ensure there is follow up on results from Mind the Gap survey
- ◆ Improve PE information resources and create easier access
- ◆ Maintain links with other PE leads and providers within the Centres
- ◆ Share information gained at the event with colleagues
- ◆ Review language used in PE and make more user friendly
- ◆ Build better relationships with Outpatients depts within the Centres to increase levels of understanding about the roles of charities
- ◆ Analyse and understand how my organisation can get involved
- ◆ Improve presentation techniques
- ◆ Feedback the importance of peer support and encourage its development
- ◆ Experiment with 'Theme of the week' idea to promote and encourage PE take up.
- ◆ Review PE programme

7. Next steps

Aspire and MASCIP will collaborate over the coming months to identify a work plan and contact any Centres requiring specific information and support from the event directly. Regular updates will be provided to delegates and some information will be shared via the MASCIP membership if appropriate.

8. Conclusion

Feedback on the day and results from the evaluation forms have shown that the event met the needs of the delegates and that everyone took useful information, knowledge and contacts away with them. Many found the opportunity to share experiences with colleagues in other Centres extremely beneficial and provided an invaluable time for networking and troubleshooting. There was a consensus that an annual event provides a much needed forum for those working in Patient Education and there was considerable support for a 4th event in 2020. Information gained on the day, coupled with the outcomes of the patients focus groups, will provide a clear work plan for MASCIP and Aspire for the coming year that will focus on the needs of

the patients and to support the Centres to deliver more effective patient focussed patient education.

Appendix 1 – Focus group report

Patient Education

Focus Group Evaluation Report

Background

This project was undertaken to establish a benchmark of patient views on Patient Education which would inform future work within Aspire, highlight and promote current good practice within the Centres and identify areas where small but significant changes would improve patient experience.

Currently there appears to be no organised forums within Spinal Cord Injury Centres (SCIC) to encourage and record group discussions involving inpatients and outpatients to obtain views specifically about Patient Education. Whilst the patient view is clearly being sought in one to one sessions during rehabilitation and some evaluation work done after each session, a collective representation of views from people with a spinal cord injury (SCI), (both inpatients and those that have completed their rehabilitation and left hospital) have not been obtained. With this in mind it felt important to spend some time listening to the voice of patients and those that have undergone the Patient Education programme but have now left hospital, to establish a level of understanding of its effectiveness, its usefulness and ease of application after discharge.

There is currently a written evaluation process for obtaining patient views after attending sessions and some informal discussions take place which are fed back to session leaders or Patient Education Administrators (PEAs). Targeted one to one work is being funded by Aspire to work with patients in the National Rehabilitation Hospital Dublin, and more recently in Princess Royal SCIC Sheffield and Queen Elizabeth National Spinal Injury Unit Glasgow, three-four weeks pre-discharge to identify gaps in learning and offer additional support and learning where required. And a research project looking at the psychological impacts of Patient Education post discharge is being undertaken at NSIC Stoke Mandeville in addition to a specifically funded post working with older people to improve their experience and participation in patient education, also at NSIC Stoke Mandeville.

Purpose

- Establish an understanding of patient satisfaction regarding Patient Education
- Identify areas for improvement
- Celebrate good practice
- Consider potential development opportunities
- Identify key information for future planning of Patient Education

Method

As previously mentioned, Aspire approached a number of SCIC's and identified three that were willing to work in partnership to deliver one focus group each. The Centres agreed to invite 8-10 inpatients and people who had already been discharged, for an informal but structured discussion. Sessions were by invitation or prior request, they were not an open session and a series of pre-set questions were formulated to promote discussion if required. Each session was led by Aspire's Patient Education Manager to ensure consistency and a separate note taker employed by Aspire was present. Sessions were an hour and a half in length with a 15 minute break. Hospital staff were not included in the discussion and were not present at the group.

Outcomes

The proposed outcomes for the focus groups were:

1. Availability of additional information to feed into the maintenance, development and continual improvement of Patient Education for the benefit of SCI patients.
2. Evidence based information to be available for future planning and funding applications.
3. Identification of a core group of SCI patients for other potential consultation exercises and provide a platform for views to be heard.

The Focus Groups

Focus groups took place in London SCIC, Stanmore, Welsh SCI Rehabilitation Centre, Cardiff and Queen Elizabeth National Spinal Injury Unit, Glasgow. There were between 8 and 12 people with a SCI injury at each of the sessions with a mix of both patients and those that had left hospital. Hospital staff were not involved in the meeting and apart from a short introduction from the main hospital contact for the work no staff were present for the group duration. Discussions were informal, but facilitated, and focussed on Patient Education. In all three groups the discussion flowed well and participants were enthusiastic and willing to share their views. Key points were recorded and a summary of those are listed below. General feedback from participants were positive and all felt it was a useful exercise, some felt it should be repeated every few years at least.

Summary of key points

1. General satisfaction with sessions, they are run very well, and very informative. Formal input on subjects is useful and speakers are knowledgeable. Opinions were that there is always the opportunity to learn something new.
2. Social discussions with other patients are informative and enlightening. Sometimes more information filters through this way than from information received from staff/nurses.
3. Tea, coffee and biscuits – patients felt this is an important part of the session too as it makes for a more comfortable, sociable session. Not all Centres provide this but it seems to be a common theme that it would encourage more patients and creates a less 'classroom like' environment.

4. Venue is important, it needs to be somewhere that is easy to hear speakers, comfortable temperature and free from interruptions. Classroom/lecture type settings are off-putting and feel too formal, patients feel less comfortable to speak and ask questions.
5. People that had left hospital reported that life isn't how they expected it and an opportunity to revisit Patient Education sessions again would be useful.
6. Peer support was felt to be a vital and essential part of the Patient Education Programme and where there was a peer present at the session it provided an insight that hospital staff were unable to give. Conversations with Peer Support were felt to be very important, worthwhile and invaluable. Peer support should be an integral part of every session – "it's easier to talk with someone who has gone through the same rehab journey as me".
7. Each Centre has their own Patient Education programme and whilst there are core subjects patients felt that for them there were some areas that weren't covered i.e. Wheelchairs and equipment, Money matters/Welfare Benefits.
8. Patient Education needs to take a higher profile and be promoted more within the Centre. Patients felt that often other issues take priority and also that the importance of attending the sessions are not always conveyed. It was recognised that it is always the patients' choice to attend but that the relevance to individuals to attend the session is not always clearly identified.
9. Provision of appropriate, timely and accessible information was a theme across all the groups. Patients reported either not being able to use the information provided by Centres or that they weren't sure how to find information. Being able to access information on Patient Education information on leaving hospital was reported as being something that would be really useful.
10. Cancelled sessions were felt to be frustrating and demotivating, particularly when it is last minute and patients are already at the session. It was felt that a contingency session should always be offered rather than sending people away.
11. Some patients are excluded from sessions, which participants felt unacceptable, those on bed rest and some vented patients are often unable to attend sessions. This may be down to not having staff available or the space to accommodate beds within the room.
12. Some of the language used in presentations can be too clinical and could be more 'user friendly', some patients felt a bit intimidated by the use of clinical terminology and wouldn't always feel confident enough to ask for explanations.
13. An 'induction' to Patient Education would be useful. Some of the PEA's give out leaflets and will chat to patients but this does depend on catching patients and whether patients are ready to listen.

What Next?

Each Centre that hosted a Focus Group has received feedback directly regarding their individual comments and will respond accordingly to any issues that directly impact on patients within their Centre. The next stage will be for Aspire Patient Education Manager to formulate an Action Plan based on the information gained from this project which will in turn be included in a work programme for the next 12 months. This will

involve working in partnership with all the SCICs where Aspire is currently supporting the Patient Education Programme and examine opportunities and developments that in the long term may benefit all Centres and patients.

Conclusion

It is important to point out that the general feeling of those that took part in the focus groups held all the staff involved in Patient Education in high regard and that sessions were felt useful and informative. Issues raised were focussed on improvement and where it was felt there was a gap in provision. Information gained from this project will play a significant part in highlighting development work for Patient Education for Aspire and the SCIC's and will provide evidence where funding may need to be sought.

Patient Education is an essential and vital part of patient rehabilitation and undertaken well will provide a smoother and more comfortable transition from hospital to home, and beyond. Effective Peer Support and Information have been reoccurring themes throughout the three groups and are likely to be the initial focus of future work that Aspire takes forward. Quick wins for the Centres could be the provision of refreshments and looking at more appropriate venues. Presenters could also review presentations to explore language and, if necessary, make them more user friendly.

Overall it is felt that the project has been useful and informative and Aspire would like to thank the Centres that were able to invest time to support this initiative. A further report will be presented in early 2020 that will outline action taken and results and benefits gained.

Appendix 2 – Event flyer



‘Closing the Gap’

MASCIP Shared Learning Event - Patient Education



You are invited to the 3rd MASCIP Patient Education Shared Learning Event

WEDNESDAY 6TH MARCH 2019

10AM – 4PM

Radisson Blu Hotel and Conference Centre Herald Way, Pegasus Business Park,
East Midlands Airport, DE74 2TZ, Derby.

The focus of the event will be:

- ✚ Updating on new developments in Patient Education in SCIC around the country.
- ✚ Providing tools, developing skills and sharing resources that will create a smoother experience for patients going through rehabilitation and beyond.
- ✚ Presentations from research and evaluation projects that are examining patient experiences and benefits of Patient Education pre and post discharge.
- ✚ Provision of accessible, appropriate and timely information.
- ✚ Peer involvement within available resources.

This is a FREE conference for staff working in Spinal Cord Injury Centres who have a focus or interest in Patient Education, places are limited and will be allocated on a first come first served basis

To book your FREE place please contact Wendy Carnell at wendy.carnell@aspire.org.uk or 07741633940

This is a partnership event between MASCIP and Aspire

Sponsored by  Coloplast

