

The joint Pressure Ulcer Prevention and Patient Safety Advocacy Project of the European Pressure Ulcer Advisory Panel (EPUAP) and EWMA is now in its third and final year.

The project is continuing some activities from the previous years, including the publishing of joint statements and articles, of which the most recent is included below this box, and a collaboration with the OECD Health Care Quality Outcomes project.

The project team is currently working on the finalisation of a generic patient case study to exemplify the patient and health economic value of preventing pressure ulcers from occurring. Case studies are a recognised way of highlighting complex problems from patients' and lay carers' perspectives. In terms of following up on the earlier organised activities with members of the European Parliament and the European Commission, EPUAP and EWMA are working to organise a roundtable session at the European Parliament during late autumn 2019.

During the EWMA 2019 conference, the joint project will host the following session. More details are available at ewma2019.org.

Thursday 6 June, 8.30 – 9.30: The joint EPUAP-EWMA Pressure Ulcer Prevention and Patient Safety Advocacy Project Session

The article below, as well as earlier articles and updates about the project, are available from the EWMA.org and EPUAP.org websites.

## Disability in Europe: The invisible burden of pressure ulcers

Over a billion people, about 15% of the world's population, have some form of disability, with 80 million of these people living in Europe. People with disabilities have the potential to make an enormous contribution to our society, culture and economy. However, they often face barriers that prevent them from participating in society and commonly do not receive adequate care. At an international level, through the EU institutions' actions and the Convention on the Rights of Peoples with Disabilities (CRPD), EU member states committed to cooperating to ensure the rights of

EU citizens with disabilities. These include the right to participation in society on an equal basis, as well as the rights to good quality of life and health. Despite this commitment, there are still many unaddressed challenges to meet the health needs of people with disability.

Depending on the group and setting, people with disabilities encounter greater risks of comorbidities, age-related and secondary conditions, compared to their counterparts without disability.

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Conflicts of interest: None As a result, they have a higher rate of premature death. Furthermore, these people are particularly vulnerable to the deficiencies in healthcare delivery, yet these deficiencies can be addressed to avoid morbidity and premature mortality.

Secondary conditions commonly occur in addition to (and related to) the primary health condition, thus, they are predictable and often preventable. In the case of people with disabilities, these conditions include urinary tract infections, osteoporosis, avoidable pain, and pressure ulcers. Pressure ulcers, also known as bed sores, pressure sores, or decubitus ulcers are wounds caused by constant pressure on the skin and underlying tissues, arising because the person sits or lies in one position for too long, not being able to change the position actively. They usually develop on body parts such as the elbow, heel, hip, shoulder, back, and back of the head. People with disabilities who are bedridden, or use a wheelchair, have a high risk of developing this secondary condition which can lead to further disability, decreases in mobility, loss of independence, increased isolation, the need for surgical interventions, and even fatal infections.

The risks factors for pressure ulcers in people with disabilities are multiple: reduced mobility or paralysis, injury completeness, moisture from bowel or bladder incontinence, loss of feeling, muscle atrophy and being underweight. A constant monitoring of those at risk is essential to enable prompt action and to avoid leaving symptoms unnoticed (when the person has sensory issues, they may not feel the intense pressure being placed on an area of the body).

People with Spinal cord injuries (SCI) often develop pressure ulcers, and in this population, pressure ulcers are a serious complication, which often lead to regular hospitalisations, multiple surgeries, and other devastating complications. Although preventable in most situations, pressure ulcers may disrupt rehabilitation, prevent people with SCI from working, or participating in society, and therefore interfere with their community reintegration. Data from the United States revealed that people with SCI are among the highest risk population for developing pressure ulcers; the incidence in SCI population is up to 66%.<sup>2</sup> Furthermore, the lifetime risk of developing a pressure ulcer among those with SCI is up to 90%.<sup>3</sup>

Acting to improve quality of care of those in need is not only possible, but also necessary. For those who use a wheelchair, or are bedridden, preventing secondary conditions, or comorbidities is a life-long commitment which requires understanding, cooperation and initiative. Col-

laboration within healthcare team is essential to develop a prevention plan that includes effective strategies and all possible actions – from position changes to use of special cushions and mattresses, ensuring adequate nutrition and hydration, and daily skin care. Also, pressure ulcer care requires constant monitoring, thus rehabilitation nurses should use a consistent framework with accurate quantification to assess, document, and monitor changes in the individual and the pressure ulcer over time.

EPUAP and EWMA are at the forefront of raising the awareness at EU level about pressure ulcers, wound care and patient safety. The commitment and expertise of these groups have been instrumental in building support for a consistent epidemiology measurement and methodology in Europe. Looking at the challenges of disabilities and health outcomes, EPUAP and EWMA believe that the EU has a role to play in guiding and supporting its' member states to increase awareness of the needs of people with disability and include related secondary conditions as a component of national health policies and programmes. It is also essential to promote strategies to ensure that people with disabilities are knowledgeable about their own health conditions and risks. Informal carers should also be educated.

Building on the current European Disability Strategy 2010-2020, a follow-up strategy shall look into creating synergies amongst member states on better health services for people with disabilities and the prevention of costly secondary conditions. In this sense, the Academic Network of Disability Experts (ANED), supported by the European Commission and the EU countries, might be instrumental in providing new analysis and information on national disability policies and the impact of secondary conditions, such as pressure ulcers.

Join EWMA and EPUAP campaign on pressure ulcers' prevention and help to spread our message #Europe4PU-prevention.

## REFERENCES

- World Health Organization, Disability and Health: key facts, available at: https://www. who.int/news-room/fact-sheets/detail/disability-and-health
- 2. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3831318/
- Kruger E A, Pires M, Ngann Y, Sterling M & Rubayi S, Comprehensive management of pressure ulcers in spinal cord injury: current concepts and future trends, J Spinal Cord Med 2013, 36, 572-85.