

ARE CARE OPTIONS OFFERED TO THE PHYSICALLY IMPAIRED ENABLING OR DISABLING?

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‘Empowerment is considered key to independent living’

The status of disabled people within UK society has recently seen major advances with the support of the government through significant changes in statute (Disability Discrimination Act, 1995; The Equality Act, 2010) and heightened media presence, from events as diverse as the Paralympic Games to the plight of the injured from military conflict. This article looks at whether society’s attitude has kept pace with these social and legal developments, and whether the physically impaired are adequately enabled to prevent pressure-related complications related to their

It could be argued that those working within, and on behalf of, health service providers should be the most vocal advocates of those with a disability. They have first-hand experience of the challenges that clients face daily, have insight into the limitations posed by long-term conditions, disease and injury, and also how clients handle these.

However, professionals frequently focus on a medical model of disability (Hughes, 2010). This concentrates on the individual’s disability as the problem and aims to define, grade and categorise conditions. Although this approach is important in identifying treatment priorities, it does little to recognise that disability is a life experience of physically impaired people, an experience that Goodall (1995) describes as ‘restrictive, oppressive and frustrating’. Goodall states that disability exists at the meeting point — the interface between person and environment.

This differing view of disability is characterised in the ‘social model of disability’. This states that disability is not about physical limitations, but rather how the physical and social environment imposes limitations on certain groups or categories of people (Hughes, 2010). In this way, ‘impairment’ (a long-term characteristic of an individual that affects their body, mind or senses) is fundamentally different from

‘disability’, which is the result of exclusion because of barriers society puts in the way.

The social model encapsulates the ideas of patient-centred care. It recognises that despite having severe physical impairment, the individual can still make autonomous decisions and direct his/her care according to individual choices and wishes (Williams, 2006). This idea may be linked to the concept of ‘empowerment’, a phrase often quoted in nursing manuscripts and one which the Royal College of Nursing (RCN) describes as a central part of nursing (RCN, 2003).

Empowerment is the process of helping people to make informed decisions in order to manage factors that affect their lives (Bethell et al, 2006). It involves providing advice, education, information and practical support that helps the patient and/or carer to establish an acceptable level of control over the management of their condition and the problems their condition might pose to health, employment and social interaction.

Empowerment is considered key to independent living. Conversely, independent living empowers people (Ratzka, 2005). Kosciulek (2004) proposes that when people with disabilities have control of important resources, they are better able to determine the course of their lives, solve problems and develop adaptive networks.

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Figure 1: Innovative new designs can remove the stigma attached to pressure care.

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This idea resonates in the recommendations of the World Health Organization [WHO] (2001), which recommended a rethink of care provision and advocated that service providers place stronger emphasis on participation, self-determination and opportunity for those with impairments.

PRESSURE ULCER RISK AS A DISABILITY

For those with conditions that limit movement, sensory perception and/or vascular perfusion, there is an increased risk of pressure-related tissue damage — a potentially life-changing, life-limiting or life-threatening event (Stephen-Haynes, 2011). Pressure ulceration occurs as a result of the interplay of unrelieved pressure, shear and friction (European Pressure Ulcer Advisory Panel [EPUAP], 2009).

If these forces are incorrectly managed, localised tissue necrosis develops leading to skin and soft tissue breakdown and wound formation. This has consequences for local tissue viability and offers the opportunity for local infection and widespread sepsis (Stephen-Haynes 2011).

Current guidance on pressure ulcer prevention focuses on the care of individuals in environments, such as hospitals and care homes (National Institute for Clinical Excellence [NICE], 2005; EPUAP, 2009). This guidance reiterates the importance of risk assessment and the provision of care packages that identify high risk activities and environments, and the implementation of strategies to reduce risk. However, although well-meant, these documents often fail to recognise that for those with physical impairments, the maintenance of a normal lifestyle is equally important.

A high proportion of these individuals will be living and possibly working within the community and many may not want regular contact with healthcare services; indeed, some view reliance on healthcare as failure.

Gibson (2002) in a descriptive research study of young men with spinal injuries found that those interviewed wanted to self-manage and return to as active a life as possible; the need for clinicians' assistance raised the threat of hospitalisation and a loss of empowerment (Gibson, 2002). If we are to empower individuals to self-care and optimise opportunities, it is essential that we provide them with the tools to do this.

UNDERSTANDING CARE WITHIN THE HOME

For many with a physical impairment, the care environment is their own home. Adaptations can be made to enable independence, such as the widening of door frames and redesigning of bathrooms and kitchens to facilitate self-care. If that is not practical, adaptations can be made to enable formal and informal carers to maintain a quality lifestyle. However, the bedroom holds particular significance to both the individual and their carer due to the physical and societal emphasis placed on it.

In our society, the bedroom and the bed itself are more than simply somewhere to rest and sleep. Although this role is important, for many of us, the bedroom is an area where we can have 'me time' to ponder life events or simply read a book. The bedroom is also the principle area in which people display intimacy and sexual behaviour.

Sexuality is a key facet of the human experience: 'A central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction' (WHO, 2002). This applies to those with a physical impairment as much as any 'able-bodied' individual.

Yet, for those with impairments, the bedroom, and specifically the bed itself becomes an area where many nursing procedures, such as catheterisation, bowel care, wound care and medical/clinical assessments are carried out. The performance of such medical roles impacts on the special status afforded this area, particularly when equipment designed primarily for formal care environments is used.

As Bowden and Bliss (2009) discussed in relation to the use of hospital beds in home palliative care, the introduction of equipment can have a significant impact on the understanding of patients and their families regarding the concept of 'home'

This can result in a perceived loss of control, self-expression, refuge and privacy as well as intimacy, sleep and relaxation. The introduction of equipment can have a significant impact on patients and their families understanding of the concept of 'home'.



Figure 2: Travel dynamic mattresses are designed to fit divan beds, such as those found in most hotels and can be set up by travellers who have a disability.

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A number of care and equipment providers have started to recognise the importance of these complex social considerations, particularly when there is a need to incorporate mattress provision that includes facilities for partners.

In addressing these requirements, they are deploying double-sized therapeutic mattresses and are exploring the options with innovative solutions such as the Dream Flow concept, (www.dream-flow.co.uk), a domestic divan bed that incorporates a dynamic mattress and is designed to overcome the stigma associated with ‘medicalised’ equipment.

CARE AWAY FROM HOME

Despite changes in the law regarding disability discrimination, the physically impaired still face problems in preventing pressure damage when they travel away from home. For most of the population, such activity, whether for pleasure or on business, is reasonably straightforward. However, these environments can pose specific issues for those with physical impairments.

Under the provisions of the Disability Discrimination Act 1995, providers of goods, services and facilities are required to make ‘reasonable adjustments’ for people with a disability. While hotels make provision for the physically impaired, the facilities offered in ‘disabled hotel rooms’ are limited. In most circumstances this extends to wheelchair access and ramps and may include grab rails and raised toilet seats.

However, provision of specialist support surfaces is extremely rare. Instead, provision of equipment to ensure personal safety is left to the individual. For those with limited movement or poor tissue vascularisation, prolonged positioning on a sprung divan bed may result in tissue damage. The individual, therefore, needs to put measures in place to reduce risk.

The subconscious action of repositioning by gross movement, such as turning in bed or through subtle changes in body posture periodically relieves tissues of the stresses which cause hypoxia (Maylor, 2001a). However, those lacking normal sensation or those unable to make such movements require frequent manual repositioning by the individual or by a carer to mimic this action. This is time-consuming, disturbs

natural sleep patterns for both the individual and the carer, and can be difficult to manage.

In dedicated care environments, other strategies are employed including the use of positioning and pillows to spread body-mass over a large surface area (as in the 30° tilt method — Preston, 1984), the use of conforming foam mattresses or overlays, or the use of dynamic alternating air mattresses.

However, in the community, particularly when sleeping away from home, these approaches may have drawbacks and limitations. They are often bulky, difficult to store and handle and in the case of visco-elastic overlays may be heavy. Even the use of additional pillows to facilitate 30° tilt positioning requires at least five pillows (Preston, 1984; Maylor, 2001b).

Most hotels offer two pillows per person and requesting additional pillows from hotel staff can prove difficult and may incur an additional charge. Self-provision of pillows is also problematic as they are bulky and in addition, departing hotels with armfuls of pillows (even if they are your own) can lead to embarrassing challenges from hotel staff.

Some new approaches to pressure relief in these situations have been developed, for example, the new generation, low profile, portable dynamic overlays such as the Travel Flow™ (www.squirrelmedical.co.uk) which is designed to fit divan beds such as those found within most hotels, can be set up by disabled traveller and are discreet in appearance.

CONCLUSION

If we are to enable the physically impaired to integrate fully into society, but avoid the complication of pressure ulcer development, a change in equipment selection and provision is needed. Clinicians need to be aware of more than just the medical needs of the impaired individual — they also need to recognise and take into account social requirements.

Similarly, equipment design and availability needs to fulfil these requirements and be tailored to include aesthetic considerations and psycho-social factors, such as the need to determine where care is provided and the maintenance of intimate behaviour. When used, equipment needs to enable, and not further disable or stigmatise, the user. **WUK**