Introduction
Adverse life experiences and stressful situations, though commonplace, can be detrimental to our health from physiological, mental and social perspectives. The death of a loved one or significant friend, for example, is a traumatic situation that we are all likely to face at some stage in our lives, but our individual methods of coping are likely to vary. Bereavement, loss and grief are terms typically associated with the stress of such an event, but these terms may bear relevance to a wider range of adverse life experiences which may all have profound and lasting impacts on our lives. Our responses to such stressors – physiological, emotional or behavioural will be as individual and complex as each of us.

This is especially pertinent for people with learning disabilities whose particular vulnerability to adversity has been recognized at Governmental level. In The Health of the Nation: A Strategy for People with Learning Disabilities (DH 1995), it is suggested that ‘Life events, such as bereavement...may therefore cause a person with learning disabilities to experience symptoms of stress reactions more readily than other people.’ In my capacity as a 3rd year student nurse (learning disability branch), I would contend that the apparent predisposition of people with learning disabilities to stress reactions is attributable to a combination of internal and external factors.

Impairments in communication and cognitive abilities may contribute to people with learning disabilities being less able to interpret situations and develop effective coping strategies for difficult situations. In addition, established social stigma, limited influence in decision-making, historically paternalistic care regimes and the ever-changing service delivery frameworks have all potentially contributed to enhanced exposure to adversity and emotional trauma for this social group. Certainly during my ten years of working with people with learning disabilities and nearly three years as a student nurse, I have encountered various service users who have experienced significant losses and adversities. Unfortunately, many of these
individuals have had their stress and grief responses negated, misinterpreted or unrecognised altogether.

What is being increasingly recognised is that people with learning disabilities are more prone to physical and mental health issues than those in wider society, yet experience greater problems in accessing appropriate services (DH 1998; Hardy et al 2006). Valuing People (DH, 2001) recognises this disparity and sets out a strategic framework for action, indicating that ‘...inequalities in health cannot be tackled without dealing with the fundamental causes.’ However, it is apparent that, until recently, there has been scarce interest or research regarding the impact of loss on people with learning disabilities. Accordingly, it is not surprising that appropriate support services or networks prove difficult for people with learning disabilities to access or are not available at all (Elliott 2003). As professional carers we should strive to provide effective support when it is needed – failure to do so is to potentially exacerbate the personal challenges many of our service users already face.

Theoretical Analysis

Any situation where someone is separated from someone or something they value can be traumatic, causing a ‘stress response’, definable as a combination of physiological reactions, behaviours, thoughts and emotions (Resick 2001). An individual’s specific response will depend on their perception and appraisal of the situation which will, in turn, depend on various internal and external factors. For people with learning disabilities, such factors may include sensory and cognitive processing impairments, limited communication skills, prevailing emotional [in]stability, the physical environment, support networks, medication regimes and so on. Even prior stressful experiences may be influential in shaping responses to future adversities – the ‘vulnerability perspective’ purports that such emotional traumas can impair an individual’s ability to cope with new or additional stress (Bar-Tur & Levy-Shiff 2000).

Significant loss, stemming from traumatic incidents and adverse life events, can threaten an individual’s sense of security or confidence by undermining their previously held assumptions about the world (Murray 2001). Faced with such adversity, an individual may feel that they no longer have control of their lives and the world may appear an unpredictable and frightening place. To regain control, people need to be able to re-organise their lives and sense of self, adjusting to life in their new situation which, broadly speaking, is the process of grieving (Bar-Tur & Levy-Shiff 2000; Murray 2001). Raphael (1984) defined grief as ‘...the emotional response to loss...’ and Lieberman (1982) suggested ‘Our feelings after a loss are the price we pay for our attachment to other people.’ However, there are various contrasting theoretical standpoints about the association between loss and grief and how these should be managed. In brief, these include the following:

Attachment Theory & Separation Anxiety: Bowlby (1980) believed that people form emotional bonds with others due to a need to feel safe and secure. He conceptualised grief as ‘separation anxiety’ – the response to breaking such an attachment bond – leading to withdrawal, apathy and despair.
Psychosocial Transitional Theory: according to Parkes (1971, 1993), psychosocial transitions are caused by life events which happen over a short period (such that there is little time for adjustment) but have a profound impact on the person’s thoughts and assumptions about their world. Additionally, the impact of the transition is expected to be enduring rather than short-lived, typically associated with emotional trauma and the development of mental health issues.

Comparison of Psychological & Physiological Trauma: Engel (1961) compared the psychological trauma of losing a loved one to the physiological trauma of severe bodily injury. He equated the process of mourning to physical healing – returning the individual to a state of health and well-being.

Tasks of mourning: Worden (1991) defines grief as an individual’s experience of their loss, while mourning is the process which occurs after that loss. He conceptualises this process as a series of tasks, implying that the individual, and therapeutic interventions from others, can actively influence the mourning process. The tasks are to:

- accept reality of the loss;
- work through the pain of grief;
- adjust to new environment;
- emotionally relocate the deceased and move on.

Whatever the theoretical perspective, the literature seems to broadly acknowledge that grieving is a normal, yet individualistic, process which commonly constitutes passage through sequential phases or stages. Progression through the process may well be fluid and a person can regress or progress on the path to resolution or acceptance with no fixed timescale (Worden 1991; Oswin 1991; Murray 2001). Unfortunately, from the literature and my practice experience, this journey often seems to be especially problematic for people with learning disabilities and those who care for them.

Double Jeopardy of Learning Disability
People with learning disabilities have the same rights to grieve as anyone else, yet historically this has been poorly recognised and supported, with such individuals often actively excluded from mourning rituals (Oswin 1991). Possible reasons for this could be the established Western culture of death being a ‘taboo’ subject, or an inherent societal assumption that those with learning disabilities lack the necessary emotional capacity or cognitive functioning to appreciate loss. What may also be difficult to acknowledge, particularly for professional carers, is that people with learning disabilities may already have an established experience of loss - acute, chronic (long-term, ongoing adversity) and successive losses (Bennett 2003; Summers & Witts 2003).

Successive losses often occur for people with learning disabilities when life-changing decisions are made on their behalf by people who do not really know them. For example, the programme of de-institutionalisation over the last thirty years may have had the laudable aim of reintegrating a marginalised social group back into society, but the potential negative impact of the move on hospital residents was under-estimated. For many people with learning disabilities, the reality of de-institutionalisation was having to leave a familiar home, peers
and way of life to live with strangers in a new home with carers previously unknown to them.

Oswin (1991) suggests that there is a tendency for carers to focus on the abnormality of learning disability rather than the normality, often failing to acknowledge the attachment bonds individuals with a learning disability can make, or the emotional implications of losses they experience. Any established impairments in service users’ cognitive functioning or communication can compound carers’ misperceptions, increasing the likelihood of appropriate bereavement support not being made available. All of these factors are considered to predispose people with learning disabilities to a greater risk of ‘atypical grieving’, which may be indicated by absent, delayed or distorted manifestations of grief (Worden 1991; Murray 2001). Additionally, there may be an emergence of, or increase in, behavioural difficulties (Conboy-Hill 1992; Elliott 2003) or co-morbidity with mental health disorders such as depression (Worden 1991; Murray 2001).

Should carers or clinicians misinterpret an individual’s presenting behaviours or attempts to articulate feelings, there is a considerable risk of ‘diagnostic overshadowing’ (Summers & Witts 2003). Misinterpretation or flawed assessment of the situation may result in inappropriate behavioural or pharmacological interventions being instigated (Bennett 2003). At the very least, such responses will do nothing to provide appropriate bereavement support to the grieving individual and may even exacerbate the individual’s challenging behaviours, social withdrawal or psychopathology.

However, should a loss or bereavement issue be identified for a service user, carers should also be wary of inadvertently attributing all the individual’s presenting behavioural, emotional or health issues to it. The individual may still have other unrelated problems which may need to be addressed. However, as a student nurse, I have encountered several service users whose grieving behaviours have been mistakenly identified as ‘challenging behaviours’ or simply attributed to their having a learning disability, apparently substantiating the concept of diagnostic overshadowing...

One such encounter was with ‘Ted’ (a pseudonym), a non-verbal gentleman with Downs Syndrome and profound learning disability, during a placement with a Sensory Impairment Service (SIS). Ted had attended the SIS for monthly ear care for several years, but had always been very sensitive and anxious about receiving examinations and treatment. For approximately four years he had received consistent support at SIS appointments from one carer with whom he had an excellent rapport, helping to alleviate his anxiety. Unfortunately, the carer died unexpectedly following a short illness and subsequently Ted’s concordant behaviour at SIS appointments declined rapidly as his anxiety escalated once more.

Following the carer’s death, a variety of different staff brought Ted to appointments, but notably none had the same quality rapport with him. When I asked escorting carers how Ted was coping following the death of their colleague, I was told: ‘He’s fine at home. We haven’t told him she died, just that she doesn’t work with us anymore. He wouldn’t understand.’
It transpired that the late carer had actually been a volunteer driver who helped with community outings and clinical appointments (hence her consistent attendance at the SIS with Ted). I hypothesised that Ted may have appeared settled at home because he made no association between the lady and his home life, rather that he had made a strong attachment to her in the context of visits to the SIS. To me, it seemed plausible that the lady’s involvement with Ted at the SIS had constituted a significant relationship, yet had ceased quickly without him receiving an adequate explanation as to why. Ted’s current carers did not appear to consider her loss to be of significance – perhaps because she played a small part in his life. Hence, they had not considered a possible association between this event and his recent escalation in anxiety at ear care clinics or identified that Ted may benefit from some form of therapeutic support.

Conclusion
Hopefully, this paper has challenged the societal construct that bereavement and grief are just about death and carers and clinicians who care for people with learning disabilities will be able to reflect on their practice accordingly. Unfortunately, the potential significance of loss and bereavement in this specialist practice area only recently appears to be gaining recognition, based on the limited scope of research literature I have been able to access. However, I maintain that loss can take many forms and the impact of such experiences can be individualistic and complex in terms of emotional, physiological, psychological and sociological responses. Furthermore, various internal (cognitive, psychological, emotional) and external (societal values, environment, support networks, professional care cultures) factors can profoundly influence an individual’s responses and progression through the grieving process.

People with learning disabilities are just as likely to experience loss as everyone else (if not more so), but have particular difficulties in recognising what has happened, understanding and articulating their feelings and appreciating they may benefit from professional therapeutic support. The theoretical discussion implies that therapeutic interventions may be beneficial for such individuals – indeed, the Department of Health has strongly advocated the need to develop services for supporting people with learning disabilities in coping with bereavement, loss, change and stress (DH 1998). With greater awareness of these issues amongst service providers and the development of appropriate person-centred services, people with learning disabilities will have a greater chance to achieve their health potential, cope with adversities and enjoy a better quality of life.

References: