

The BILD Positive Behaviour Support International Research and Practice Conference 2014

Defining PBS and promoting evidence based practice

8 - 9 May, Glasgow



BILD's 2014 Defining PBS and
promoting evidence based practice – 8
May

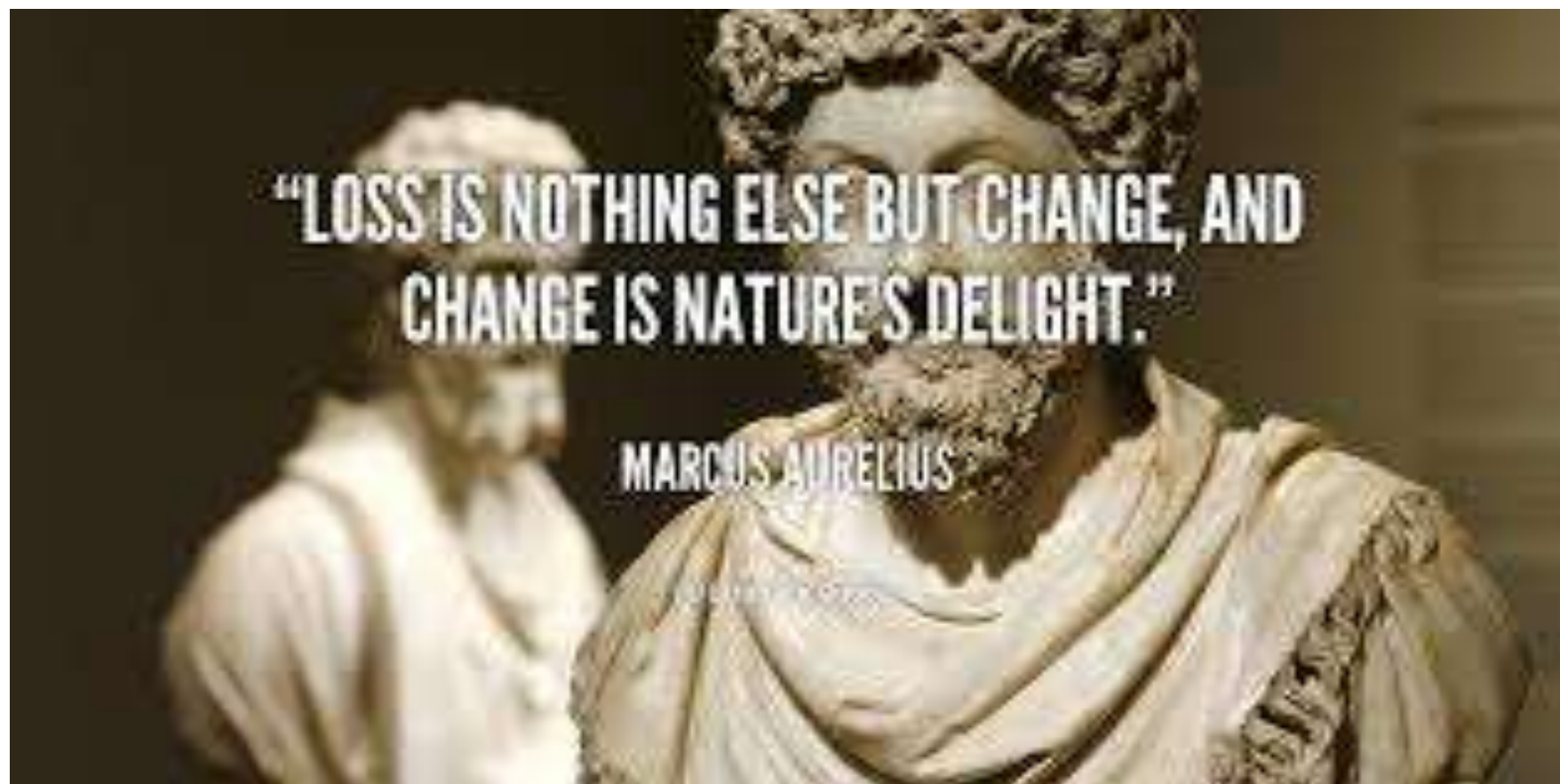
Workshop 3

Supporting individuals with autism through change
and loss

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BILD PBS Conference 2014

Defining PBS and promoting evidence based practice



Change and Loss

Change and Loss in some form is common to everyone and perhaps affects our daily life more than we acknowledge.

Some common losses experienced are;

- The loss of school friends, these are replaced by work colleagues
- Loss of a family home
- Breakdown of family relationships
- Loss of hair and physical abilities due to old age
- Loss of a social acquaintance who has moved away.

Change and Loss

The most catastrophic loss, however, is usually brought about by the death of a person.

The death of a loved one or the death of pet is termed as a traumatic loss, however the loss of a significant object(s) can be just as traumatic for the individual involved.

Bereavement is defined as “the loss of something that is precious”
(Good grief 2 1989)

Change and Loss

We are all individuals with our own views, beliefs, opinions and life experiences, therefore reactions to a loss/bereavement will be unique to the individual involved.

Whilst these losses can evoke very strong emotions, with good support it can be argued that these losses and subsequent changes are a necessary part of life.

Change and Loss

Take a moment to reflect on some of your own personal losses you may have experienced throughout your life.

How did these losses make you feel? and how did you cope with them?

Change and Loss

Most people do not feel comfortable discussing death perhaps because it faces us with our own mortality. Bereavement and the feelings that it evokes is considered a taboo topic in western society.

Individuals with autism and those who appear to be “different” can also be avoided by neuro-typical society. It therefore makes the experience of change and loss more difficult for those with autism.

Change and Loss

There are many factors which influence how people behave immediately after a death and how profound and long reaching the process of bereavement may be.

The manner of death is a very important factor in determining how a person copes.

The intensity of shock and grief is likely to be much less for the survivors if the death was expected than if the news is sudden.

Change and Loss

Time scales seem to matter a great deal to people, they can adjust mentally and emotionally to the coming traumatic period if they have some idea when to expect the death.

This especially beneficial for individuals with autism, and time should be used to promote their understanding of how the death/change will affect them, for example grandparents no longer available to collect them from school, or visits to parental home may cease.

Change and Loss

How information is presented to the individual should be considered and planned.

- Use language appropriate to the level of the individuals understanding
- Tell the truth, without giving unnecessary or disturbing details
- Don't expect the individual to respond in an "acceptable" manner
- Observe how they may appear to be feeling
- Allow the individual to realise their feelings
- Difficulty in understanding facial expressions, body language and tone of voice.

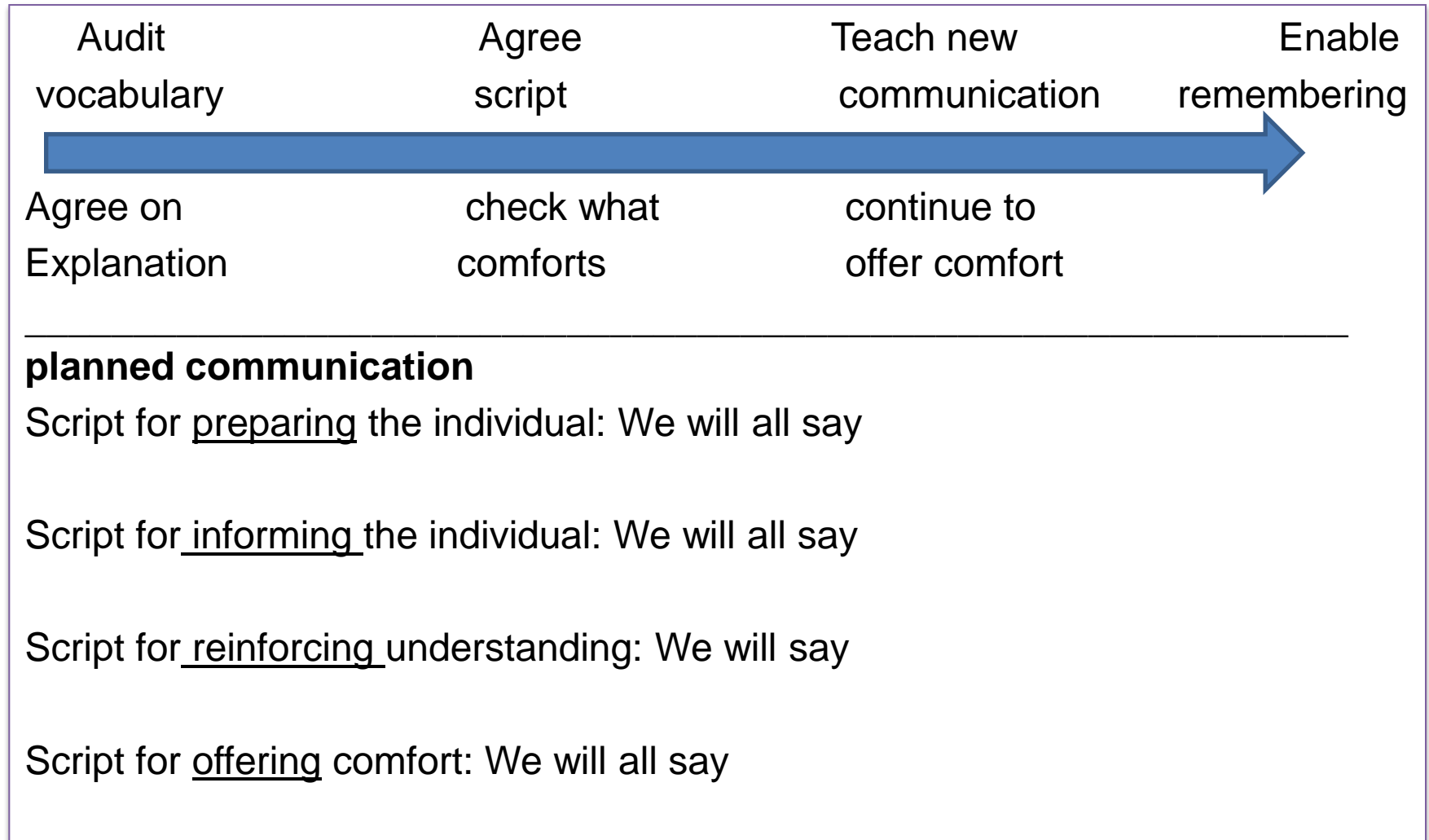
Change and Loss

The best approach is to be factual about the forthcoming loss, so there can be no hope of return or seeing the person again.

Family's may wish their son/daughter to be informed that the deceased has “gone to heaven” or “is with Jesus”, this wish should be respected by the staff supporting the individual.

If the individual has experienced a previous loss/bereavement, it is important to explain any subsequent losses in the same manner.

Essential communication







Change and Loss

Some individuals with autism, might require a more detailed explanation and opportunity to explore their own concepts of death and after life beliefs. Whilst others might be confused by any more than minimum information.

Therefore staff must be prepared to respond with flexibility, depending on the individual's capabilities.

Worden's Tasks of Mourning

<p>Task #1</p> 	<p>To Accept the Reality of the Loss</p>
<p>To Work Through the Pain of Grief</p>	<p>Task #2</p> 
<p>Task #3</p> 	<p>To Adjust to an Environment in Which the Deceased is Missing</p>
<p>To Find an Enduring Connection with the Deceased While Embarking on a New Life</p>	<p>Task #4</p> 

Adapted from Grief Counseling and Grief Therapy, 4th ed. by J. William Worden (2005) <http://www.grief.com>

Change and Loss

Individuals with autism will react individually to the bereavement and the support provided must be unique to them.

Individuals with autism may share the same responses as neuro-typical people to bereavement; denial, anger and despair.

Skilled support is an important factor in helping individuals move through their grief to reach resolution.

Change and Loss

Supporting staff must be aware of the individual's communication skills, socialisation skills and flexibility of thought.

This variation in the capabilities of the individual with autism, adds a complexity into the function of the staff offering support and why it's important to tailor the care plans to their capabilities.

Change and Loss

It is impossible to be able to offer adequate support for the bereaved person with autism without having an understanding of their personality.

This knowledge of personality can only be obtained over a period of time and by building and maintaining an effective working relationship with the individual, as a basis for interpreting the grief process to the individual in their care and in order to know how and when to offer support.

Change and Loss

Who should inform the individual?

- key-worker/support worker
- befriender
- family member
- someone with whom the individual has a good relationship.

The relationship to the individual and the ability to feel comfortable when talking about death are the most important factors in the selection of a member of staff to support a bereaved individual.

Change and Loss

However there are good reasons why certain individuals might not wish to undertake this role, such as lack of experience of bereavement or concern that a bereavement experience of their own might be brought to the surface again.

No one who has suffered a recent bereavement should be asked to support a bereaved individual.

Change and Loss

It helps with the resolution of grief if the identified support worker remains supporting the individual over the course of the grieving process which can last up to two years.

That the identified support worker has a good knowledge and understanding of the relationship and activities the individual shared with the deceased, this will also help with the individuals remembrance.

Change and Loss

Ceremony's and rituals surrounding death can be used as part of the mourning process and acceptance of the death.

Individuals with autism need to be involved in this process, to enable them to complete the grieving process.

This can promote the understanding that death is irreversible and the person won't be coming back.

Preparation of what the individual can expect to see and do during the funeral should also be carefully planned. Perhaps a visit to the church would be useful.

Change and Loss

Remembering;

Individuals may need additional support on the occasion of the anniversary of the death and also at times of festivities such as Christmas, Easter and birthdays which they have shared with the deceased.

This is where the Time line should prove helpful, as it can help identify known stressors. This will enable staff to provide comfort.

Change and Loss

Factors to consider when offering support;

The individual with autism has poor or little understanding of body language and facial expression and is unable to process/ interpret what we are gesturing. Therefore they miss a vast amount of information neuro-typical individuals take for granted.

Understanding, sympathy and support has to be expressed in words or signs/ symbols.

Change and Loss

People with autism are unlikely to seek support when they are anxious, depressed or unhappy. Because of communication and social interaction difficulties, the only way they may be able to express their grief is by displaying behaviours that may challenge. It is necessary for staff to intervene sensitively.

Although a minority of people with autism do not apparently grieve when they lose someone close, the majority need to experience the grieving process and require help in order to do so.

Change and Loss

Summing up.....

- Supporting bereavement in people with autism is not about assessing first reactions only
- When you become aware of loss through separation or death, set up a long-term assessment process
- With reference dates that cover periods when the loss is likely to be most apparent to the individual concerned.

Change and Loss

Summing Up....

- In the case of loss of a significant person your assessment timetable should run for the minimum of a year. This will cover special days that may be important to the individual, including the anniversary of the loss/bereavement.
- Be ready to respond to any change in behaviour as though it were the onset of grieving.
- Use the time available to plan and script how you will support that grieving when it commences.



Change and Loss

Scottish
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Thank you