Policy / Procedure Details	Title:	**Enabling People to Enjoy Best Possible Health**
	Type:	**Services**
	Related Personal Outcome Measure:	**I Have the Best Possible Health**
	Code:	**1.6**
Original Version Details	Date Released:	**21/02/2002**
	Previous Title: *(If applicable)*	**Best Possible Health**
Revised Version/s Details	Date/s Released:	**02/02/2011**
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	Approved By:	**Executive Director**
	Date Released:	**31/10/2013**
	Monitoring Process:	**Procedural Review Process**
	Date Due for Review:	**31/10/2016**

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Policy and Procedure Feedback Form

A Policy and Procedure Feedback Form is available on the Western Care Association Intranet (under Procedures) which will provide an opportunity to comment on any policy/procedure.

Your comments will be forwarded to the person who has the lead for the on-going development of the policy/procedure.

All comments will be collated by the person responsible and will inform the three-yearly review cycle for updating procedures.

Introduction

Good health is important to everyone. It cannot be looked at in isolation but must be considered in the context of the fullness of the person's life. We are more likely to enjoy good health if we are living a contented life.

A good life is about spending our day in satisfying and meaningful ways, doing work we enjoy, living and spending time with people we care about and love and having the resources to meet our material needs. Being connected to the community and feeling appreciated through the roles we play helps us form relationships with others. When we don't have these important connections, our mental, social and physical health is likely to be impacted.

When we exercise our rights we feel empowered and in greater control of our lives and destiny. When we are involved in or have control of decisions that matter to us in our life then stress, anger, fear, worry and feelings of hopelessness are minimised and wellbeing is enhanced.

Best possible health must be considered in the context of the full expanse of the person's life. It is about having regular health checks, but not without due consideration to the level of satisfaction the person experiences in every other aspect of his/her life. Our physical and emotional health are distinctly connected to all else that we experience in our life.

We find out how good life is for the person through conversation with the person and/or others in the course of developing their Individual Plan.

Rights and Values
With respect to the Personal Outcome, "Best Possible Health" it is important to impress:

- It is a fundamental right that every person, without exception, shall enjoy the highest attainable standard of health.
- People are enabled to make informed healthcare decisions.
- People may accept or reject the advice of healthcare professionals.
- People use mainstream health services and shall not be denied access due to their disability.
- If a healthcare intervention is approved which restricts a person's rights through intrusive/restrictive practices, it will be subject to rigorous and regular review.
- On an individual and organisational level, any attitudes, practices or policies that restrict or prevent a person accessing healthcare supports/interventions will be challenged and addressed
- It is necessary to work collaboratively with healthcare providers at local, national and international level to ensure the needs of the people served by this organisation are understood and reflected in healthcare policy and provision.

The right to health does not mean the right to be healthy. While we may be living with a chronic health condition, nonetheless, we are enabled to be as healthy as we can through access to health services, adequate housing, nutrition and healthy and safe working conditions.

Lifestyle
Lifestyle refers to how we choose to live our life. As we grow older our needs and priorities change. We know that people's health care priorities differ throughout life in keeping with their changing lifestyle. As we age, we generally become increasingly more cautious, realising that we are not infallible after all. We tend to associate growing old with loosing one's health. However, it should be possible to preserve best possible health as we grow older rather than automatically accepting it as inevitable.

The food we eat and the exercise/activity we undertake during our lives, both of which are generally within our control, are major determinants in the quality of our health and general wellbeing.

It is the responsibility of staff to support the person to live healthily and take or retain responsibility for his/her health.

Nutrition
Healthy eating means eating a wide variety of food, in the correct amounts, to ensure we get all the energy and vitality we need. A healthy eating plan can be illustrated in the shape of a food pyramid which outlines various food groups and food choices that, if eaten in the right quantities, form the foundation of a healthy diet, see intranet resources.

Encouraging someone to eat healthy food can be a challenge. You may have to balance the person's right to make their own choices against the importance of having a healthy diet.

It is the responsibility of staff to ensure the person is encouraged to consume a well balanced and nutritious diet that takes account of any particular dietary needs he/she may need. For additional guidance refer to organisational policy in relation to "food and nutrition"

Exercise
Many people do not get enough exercise. Respecting the person's right to make their own lifestyle choices is important but physical activity makes people feel better, builds skills and helps prevent obesity and lifestyle diseases. Try to find something the person enjoys and then build it into their weekly routine. Seek out community based activities with people where at all possible.

Any type of exercise is good; dancing to a CD or walking to the shops. However, for people to lose weight, they need to puff or work up a bit of a sweat. The person should see a doctor before starting vigorous exercise – if he/she is ageing, has been inactive, has major health problems, has heart disease in the family or you have any other concern.

It is the responsibility of staff to support the person to access appropriate health information and education, in all areas relevant to his/her life including diet and nutrition, recreation, interests and activities.

Supporting the Person's Health - Good Practice

To support the person you must:

- Ensure the person is actively involved in their own health care and that they take part in every decision concerning his/her needs wherever possible.

- Develop a **Health Action Plan (Appendix A)** for the person. The **Health Action Plan** should be completed by the named staff based on the person's current health status.

- Assist the person to stay informed about and access health checks that are consistent with his/her age and risk factors**. (Preventative Health Care Checks - Appendix B)**. Generally speaking, people 18-65 years old should have a medical check every one to three years depending on their health and risk factors. Those who are 65 and older they should have a medical check once a year.

- Ensure the routine examination includes the GP talking to and observing the person; measurement of height, weight and blood pressure; checking immunisations and bringing them up to date. In addition, the GP should carry out any procedures that are indicated because of risk factors, age or gender. A vision or hearing test may also be included.

- Encourage the person to speak up and ask questions if they need information or have concerns. They should expect answers that can be understood, not ones heavily laden with unfamiliar medical terms. A family member or staff should help interpret and explain if required.

- Observe and follow up any specific indications which may signify ill-health. It is important that the person has routine health checks with their GP, even if they are not sick or having problems.

- Track health appointments attended throughout the year. These must be recorded using forms available in the **Health Action Plan**. This is to keep track of appointments attended, record the decision/result and identify when the next appointment is due.

- Acknowledge that the person has the right to choose not to attend a recommended health check. In such cases the person's decision should be recorded. The named staff along with their line manager needs to ensure that this decision is an informed one.

- Use guides available to help people prepare for appointments such as "Neurology Appointment Preparation" Form and "Psychiatric Appointment" Form (**See Appendix C**). Also available are Epilepsy Seizure Records, frequency/duration of disturbed sleep, behaviour observation charts, urine/bowel function, pain assessment tools, menstrual history or food diary, for instance. See intranet resources to access these.

Appointments / Consultations - Some Helpful Guidelines:

- What should the person look out for, signs and symptoms. Collect as much reliable information about the condition, tests and treatments.
- How will tests or treatments help the person and what is involved.
- What are the risks and what is likely to happen if the person does not have this treatment?
- Keep records of all the medicines being taken including – prescriptions, over the-counter and complementary medicines and any information/side effects about drug allergies he/she may have.
- Make sure the person understands the medicines being taken. Read the label, including the warnings. Make sure it is what the G.P, prescribed and the pharmacist dispensed.
- Follow up the results of any test or procedure carried out. Find out what they mean for the person's care.
- Discuss options if the person needs to go into hospital. Establish:
  - How quickly does this need to happen.
  - Is there an option to have the surgery/procedure carried out as a day patient or in an alternative hospital?
- Make sure the person understands what will happen if surgery or a procedure is recommended. Establish:
  - What the surgery or procedure will involve and if there are any risks?
  - Are there any other possible treatments?
  - Is this covered by medical card/health insurance? Are there charges/costs?
- Inform the health care professionals of any allergies or if he/she have ever had a bad reaction to an anaesthetic or any other drug.
- Ensure the person, doctor and surgeon all agree on exactly what will be done.
- Before leaving hospital, find out about the treatment plan the person will observe at home. Make sure he/she understands their continuing treatment, medicines and follow-up care and visit GP/consultant as soon as directed following discharge.

Some Indicators of a Possible Underlying Health Problem

When we take the time to get to know the person well we improve our ability to observe and understand how he/she might be feeling about what's happening in their life or health. This is especially important for people who do not use words to tell how they feel or what they might need to improve their circumstances. They may only be able to reveal how they feel by the way they behave.

Staff should alert the person and others to any changes that may indicate an underlying health problem. Some of the more obvious signs to look out for are changes in:

- Appetite
- Energy levels
- Pain or physical discomfort
- Restlessness, agitation, irritability
- Concentration or attention
- Nervousness or tension
- Headaches
- Low moods/changed moods
- Weight changes.

Some signs are not at all obvious and can be difficult to understand or interpret. However, when we know what to look out for, we increase our likelihood of being able to figure out what is amiss and subsequently improve the person's wellbeing.

Remember

- All symptoms mean something
- Any symptom can be a clue to a psychiatric or other medical problem
- The same symptom in the same person can mean something different every time it presents.
- Itching can be excruciating
- Many people may not know that they can ask for help, or have been conditioned not to ask for help
- Other signs of pain, other than change in behaviour, may be less obvious.
- Chronic pain and acute pain are experienced differently
- Medications and/or trauma history may alter reactions to pain
- Observe: - what is touched - what is numbed - what is avoided by a movement.

It is also worth considering that medical reasons alone may not explain why the person behaves in particular ways. There may be a sensory issue present which could provide an explanation.

If you Observe	It May Mean
High Pain Tolerance	• A lot of experience with pain • Fear of expressing opinion • Acute confusional state • Nerve damage/various causes
Fist Jammed in Mouth/Down Throat	• Gastroesophageal reflux • Eruption of teeth • Asthma • Regurgitation of ingested food • Nausea
Biting Side of Hand/Whole Mouth	• Sinus problems • Eustachian tube/ear problems • Eruption of wisdom teeth • Dental problems • Pins and needles – hand
Biting Thumb/Object with Front Teeth	• Sinus problems • Ears/Eustachian tubes
Biting with Back Teeth	• Dental • Inflammation/infection of middle ear
Uneven Seat	• Hip pain • Genital discomfort • Rectal discomfort
Odd Unpleasurable Masturbation	• Inflammation of prostate gland • Urinary tract infection • Vaginal inflammation-yeast/bacterium • Pinworms • Repetition phenomena – compulsion to repeat
Waving Head Side to Side	• Declining peripheral vision or reliance on peripheral vision
Walking on Toes	• Arthritis in ankles, feet, hips or knees. • Tight heel cords
General Scratching	• Eczema, • Drug effects – liver/renal disorders • Scabies
Intense Rocking, Preoccupied Look	• Pain affecting organs and soft tissues • Headache • Depression
Won't Sit	• Inner restlessness/urge to move • Back pain • Rectal problem • Anxiety disorder

If you Observe	It May Mean
Whipping Head Forward	• Atlantoaxial dislocation • Dental problems
Left Handed or Fingertip Handshake	• Frightening previous setting • Pain in hands/arthritis
Sudden Sitting Down	• Atlanto axial dislocation • Cardiac problems • Seizures • Loss of consciousness/dizzy spell • Vertigo • Mid ear inflammation, throwing off balance
Waving Finger in Front of Eyes	• Migraine • Cataract • Seizure • Inflammation of eye/corneal abrasion
Pica	• General; obsessive compulsive behaviour, hypothalamic problems, history of under stimulating environments • Cigarette butts: nicotine addiction, generalised anxiety disorder • Glass: suicidal • Paint chips: lead intoxication • Sticks, rocks other jagged objects • Endogenous opiate addiction • Dirt: iron or other deficiency state • Faeces: post traumatic stress disorder, (PTSD), psychosis
Self Restraint/Binding	• Pain • Tic or other movement disorder • Seizures • Severe sensory integration deficits • PTSD • Tingling, prickling, numbness feeling
Scratching Stomach	• Gastritis, Ulcer • Pancreatitis, also pulling at back • Porphyria- affecting skin/nervous • system. Gall bladder disease
Scratching/Hugging Chest	• Asthma • Pneumonia • Gastro oesophageal reflux • Costochondritis/”slipped rib syndrome” • Angina

If you Observe	It May Mean
Head Banging	• Pain • Depression • Migraine • Dental • Seizure • Middle ear inflammation/infection • Mastoiditis- infection of skull area behind ear • Sinus problems • Ringworm of scalp
Stretched Forward	• Gastroesophageal reflux • Hip pain • Back pain

(Ruth Ryan MD, James Salbenblatt MD, Suzanne Sundheim MD, Colorado Behaviour Pharmacology Clinics, Melodie Blacklidge MD, Cincinnati, June 1997)

If any changes are observed you should discuss this with:

1. The person concerned and their family where appropriate – do they agree?
2. The named staff and your line manager.
3. Other staff who also know the person well.

It is important to pay attention to and report/discuss any concerning indicators of ill health with relevant others.

When Pain May Be Present

People are generally living longer, which means that more people are experiencing conditions and illnesses that come with old age. Furthermore, people can often have problems being understood by others or identifying what is wrong with them. This can make describing pain very difficult.

Behaviour that challenges can often be seen as part of how people are, without considering whether anything else, like pain, could be having an effect.

Pain relief must be used instead of sedatives to control difficult behaviour which is caused by pain. The use of sedative medication as a first response must be avoided.

Past experiences, particularly of unpleasant or scary medical situations, mean that some people don't want to admit that they are in pain because they are scared of what will happen to them. Therefore, their pain is often ignored, or mistaken for behaviour that challenges. See "Listening and Responding to people who challenge and Restrictive practices" for further information.

People who aren't with the person regularly may not be familiar with the subtle changes in someone's behaviour that might show they are in pain.

Dementia, for example, can mean that the part of the brain that understands the 'geography' of the body is damaged, so people can not show where they are experiencing pain.

It is often wrongly believed that people with an intellectual disability have a high pain threshold, so those who provide support do not consider that the person could be in pain.

What you can do if you think pain might be present
Arrange for the person to see their G.P as soon as possible. Record the person's behaviour and what you consider to be signs of pain to help the G.P/consultant.

Listen to and observe carefully what the person communicates to you, through their words, actions, gestures, about how they feel. When we pay close attention, we are more likely to make a good assessment of what the person is experiencing.

Listen to the views of others who know the person well. Those who are closest to the person are more likely to observe the more subtle behavioural and physical changes and indicators that may not be evident to others.

Pain assessment tool
When someone has difficulty communicating it is important to use a pain assessment tool that looks for non-verbal signs of pain.

With the support of your line manager, and Behaviour Support staff if involved, use a pain assessment tool to help identify distress cues more clearly. The tool helps to compare how the person's behaviour changes from content to distressed state and helps establish the likely presence of pain. It helps to improve observational skills resulting in improved health outcomes for the person. They are also used to record the effectiveness of pain relief interventions.

A number of pain assessment tools/checklists are available from the organisation's intranet resources. If none of these are a good match for the person you support, consult your line manager as there are a number of alternative tools available.

All of the information gathered through discussion, observation, pain assessment and incident/injury will help the G.P/consultant make a diagnosis. It is very important that the individual attending the G.P/consultant is supported by someone who knows him/her very well.

When an individual, who cannot verbally communicate when they experience pain, is prescribed "as required" PRN analgesia, a written protocol must be in place. The indicators/circumstances in which it is to be administered must be clearly understood by all who support the person – *See Medication Policy Appendix 6.*

For some people, depending on their health status, it may be more effective to take regular analgesia instead of PRN analgesia. Regular health reviews need to be made to ensure pain relief is effective and that any side effects are being controlled.

Additional Pain Relief Considerations
Check the person's posture and seating. Are they sitting upright, can they put their feet flat on the ground? Are they well supported in their seat? Look at other ways to manage pain that don't involve taking medicine such as:

- Aromatherapy oil and massage
- Massage mattress
- Music that the person likes, favoured possessions
- Whirlpool, bubbles, peace and quiet, warm bath
- Calmly asking about the pain
- Being slow and relaxed when moving people
- Pressure sore cushion
- Special comfort chairs
- Comfort at night – blankets, warmth etc.

Helping the person to relax tense muscles may make the pain more bearable.

When the Person May be Experiencing a Mental Health Difficulty

Mental health is as important as physical health. Good mental health helps people cope with day-to-day living, major life-changing events and decisions.

Being connected to the people we love and care about is essential to our emotional and physical wellbeing. If people lack important relationships in their lives, if there is a dearth of joy and hope in their life, if they have insufficient influence and control, if they feel lonely and alone, then it is inevitable that their physical and mental health will be affected.
Mental health includes more than just a person's state of mind – it is central to well-being. It includes medical and social factors and is not just an absence of illness, but is a state of wellbeing. Our mental health affects the way we view the world, interpret events and communicate with those around us. Everyone has mental health needs.

When these are not satisfied, the person is likely to develop mental health problems. It is essential that all those who support the person recognise the importance of mental health and the impact it has on overall well-being and quality of life.

What is a mental health problem?
Sometimes a person's ability to cope with day-to-day life is put under great strain. They may not be able to function as they usually would. When this arises we say that the person has a mental health problem. There is a wide range of mental health problems. Symptoms can vary dramatically in severity and intensity. For example, one individual may develop mild depression following a bereavement and experience feelings of sadness and low mood, but may still continue their usual activities, possibly with less pleasure. In contrast, another person suffering bereavement may have great difficulty functioning, become withdrawn, not eat or sleep and may need extra care and support for a period of time.
People with mental health problems experience significant changes in the way they **think**, their **emotions** and the way they **behave**. The following are general examples of how a mental health problem can affect people.

Examples of effects of mental health problems

- **Changes in thinking:** Some people may hold unusual beliefs, be preoccupied with negative thoughts or have difficulty in concentrating. Thought processes may be slowed down or speeded up.
- **Emotions:** Changes in mood, for example feeling low, sad, elated or irritable, all or most of the time.
- **Changes in behaviour:** Such as loss of interest in activities and relationships, isolating oneself, not looking after personal hygiene or appearance, being restless or overactive. These changes impact on the way the person functions on a daily basis.

It is particularly important to be alert to changes in a person's thoughts, behaviours or feelings. Changes suggest something different is happening to the individual, and that may be a physical or a mental health problem. For example, an individual may not care much about his/her appearance, is shy, enjoys their own company and has a very limited set of interests. These are normal characteristics for the person, but if another person started behaving in this way, it could be unusual and might suggest the possibility of a mental health problem or physical ill health.

Areas that change when a person develops a mental health problem include:

- Physical state, such as increase or decrease in appetite, weight, stomach upsets, headaches
- Levels of energy and activity
- High, low or irritable mood
- Odd, unusual beliefs, which are out of character
- Problems with memory and concentration
- Reduced ability to adapt to new situations or learn new skills
- Challenging behaviour
- Personal relationships and levels of social interaction
- Physical appearance and hygiene
- Communication patterns.

What you should do if you think the person has a mental health problem

Talk with the person. He/she may be very clear about the source/reasons for their current position. For others, it may not be so straight forward. In such circumstances, the people involved in the person's life, family, staff should discuss the issue as soon as possible. They should make a list of all the changes they have observed in the person's behaviour and record the reasons why they are concerned. It is important to talk to all people in the person's circle, as the individual will have different relationships with all of them and some people may have supported the person more than others.

As good health is distinctly connected to our overall satisfaction with life, consider also what else may be happening in the person's life at this time. What, if anything, has changed and does the person have any choice or control in the matter?

It does not automatically follow that everyone who experiences a difficulty will need to attend their G.P or require referral to mental health services.

A referral to the psychology department or Behaviour Support Service (BSS) may be sufficient to address the person's needs.

In situations where a visit to the G.P or a referral to a psychiatrist is considered appropriate it is important that someone who knows the person well, family or named staff, offers him/her support when they attend the appointment. He/she should be encouraged to say what the problem is, if possible, and how they have been feeling. The family or staff member (with the person's consent) should also explain their concerns, emphasising the following:

- What changes have occurred
- When they started
- Why they concern family/ staff
- How the changes are affecting the person's day to day life.

If the person is unwilling to seek help the person's family/circle must be made aware of this decision. This becomes even more important if he/she is at risk because of the decision to decline support.

Referrals to Psychiatry - Process

- Before seeking a referral or re-referral to Psychiatry via the person's GP, the Named Staff and the Front Line manager (FLM), must meet and consider whether this is the most appropriate course of action. If such a referral is considered necessary the RSM must be notified. The RSM will consult with the area BSS and/or Psychology before authorising the approach to the person's GP for referring on to Psychiatry.
- Where staff members are aware that a family may be seeking a referral to Psychiatry via the family GP, they should also inform the RSM.
- Attending Psychiatric Appointments: When an appointment to the Psychiatric service is offered, it must be availed of regardless of which Psychiatrist is on duty.
- A copy of the Medical Appointments Forms (Appendix A) which is completed following a Psychiatric appointment, must be sent to the RSM.

To enhance co-ordination, communication and the prioritisation of work, the RSM and the BSS staff member who reports to that RSM meet on a monthly basis. The Psychologist supporting that area also meets with the RSM each month thereby ensuring that information is shared and the appropriate supports are made available to people.

When a Decline in the Person's Abilities and Skills is Suspected

Due to advances in healthcare and general living standards, life expectancies are increasing year on year within the general population and indeed within the population of adults with intellectual disabilities. With increased life expectancy, there is an increased risk of developing conditions related to older age, including dementia, for adults within the general and intellectual disability populations.

It is important to impress that many conditions can trigger an acute confusional state which may cause the person to exhibit many of the changes that are similar to those caused by Dementia.

It is necessary to consider and explore the following possibilities:

	Symptoms	**Actions**
Stress	Concentration difficulty Irritability Decline in abilities	Identify stressor Recent life events e.g. illness, grief/bereavement
Thyroid	Lethargy Weight gain Cold intolerance Changes in skin and hair	See G.P. Annual blood tests Under or over active thyroid Medication
Depression	Disturbed sleep Loss of appetite Low mood Tearful Withdrawal from usual activities	See G.P. Counselling and/or medication
Sensory Impairment	Ignores instruction Mobility problems Loss of confidence Shouting or raised voice	Undertake full health check Check eyes, ears, feet Access appropriate services
Physical Causes	Withdrawal Aggression Self – injury Pacing Screaming Crying Other	See G.P. Medical history & physical investigations Medication changes/Medication toxicity Diabetes Pain Urinary tract infection or other infection e.g. chest Nutritional deficiencies/constipation/dehydration Fractured bones- commonly hip Chronic hepatitis Vitamin deficiency – folic acid Neoplasms – tumour Head injury – seizure activity Delirium Other psychiatric disorders
Dementia	Loss of recent memory Loss of skills Changes in mood Orientation difficulties Sleep disturbances Language difficulties	Refer to G.P. and psychology initially
Sleep Apnoea	Lethargy Concentration difficulty Exhaustion/nodding off to sleep Irritability Decline in abilities	Refer to G.P. Referral to sleep clinic

Sourced, in great part: Earnshaw and Donnelly (2001)

While Dementia is an umbrella term, there are common features associated with all Dementia types, examples include:

- Deterioration of memory
- Word/name finding difficulties
- Appearing to forget verbal instruction (or seems to take more time processing instruction)
- Disorientation
- Difficulty performing daily tasks.

Currently, prevalence rates of dementia among people with intellectual disability, excluding people with Down Syndrome, appear to be similar to rates within the general population. Adults with Down Syndrome, however, are at an increased risk of developing dementia although it is important to note that not all adults with Down syndrome will develop dementia.

The higher risk of early onset of Alzheimer's type dementia among people with Down syndrome is thought to be linked to their specific neurology.

Current prevalence rates of Alzheimer's disease in people with Down Syndrome vary according to age.

- Over 40 years 20%
- Over 60 years 55%
- Over 65 years 75%

(Janicki & Dalton, 2000; Tyrell et al., 2002)

In order for a diagnosis of Dementia to be made, there must be evidence of:

a) Memory impairment i.e. impaired ability to learn new information or to recall previously learned information.
b) And one or more of the following: language disturbance i.e. word or name finding difficulties, impaired ability to carry out motor activities, failure to recognise or identify objects despite hearing and sight being tested, disturbance in executive functioning for example planning, organising and sequencing
c) The above causes significant impairment in the person's functioning and are a significant decline from previous level of functioning
d) The course of the illness is characterised by gradual onset and continuing cognitive decline
e) Other causes need to be ruled out including Parkinson's, subdural hematoma, brain tumor, Vitamin B 12 or folic deficiency, hyperthyroidism, urinary tract infection or substance induced conditions (check the side effects of medications) See also table on previous page.
f) The changes are not better accounted for by another mental health difficulty such as depression

The diagnosis of Dementia can be made by a G.P, Psychiatrist or Clinical Psychologist. Before referral it is useful to have a blood panel completed in order that medical reasons can be ruled out.

An initial referral to the GP is recommended to effectively rule out other potential physical causes, before referral on to the Psychology department for more in-depth investigations. Psychiatry and G.P.'s will also typically refer to Psychology for the assessment.

Psychology assessment in the area of Dementia uses a range of tests in order to target possible areas of decline.

The following are some signs that one may look out for or experience in the course of dementia, in no particular order:

- Deterioration in the ability to accomplish skills of daily living
- Deterioration in short term memory
- Increased apathy and increased inactivity
- Loss of amenability and sociability
- Loss of interest in favoured activities/hobbies
- Withdrawal of spontaneous communication
- Reduction in communication skills
- Disorientation and confusion
- Changes in depth perception
- Changes in night-time sleep patterns
- Increased problems with comprehension
- Increased wandering

Amongst people with a learning disability, other than Down Syndrome, the length of time that the person has the condition may be the same as the duration within the general population, somewhere between eight and fifteen years. For people with Down Syndrome there will generally be a more rapid progression.

As people with an intellectual disability may already have memory problems, difficulty with daily living skills, poor concentration, communication difficulty and poor orientation, it can be quite difficult at first to detect the deterioration in the person.

Furthermore, those who know the person well will often absorb and compensate for these changes by increasing their prompting and other support they provide without really recognising or seeing the gradual changes in the person as significant. Where the person requires a number of people to provide support, subtle changes in the person may not be noticed for some time.

However, when information is gathered by everyone involved with the person it will be possible to build a picture and discover what/if any changes are arising.

See "**Early Signs of Dementia Checklist"** intranet resources, which can be used to monitor possible areas of decline. Guidance and support in relation to its use or any other queries or concerns may be obtained by contacting the RSM/ psychology department staff.

Systematically gathering and recording information about the person's skills, abilities and behaviours across different environments can provide very important background and evidence for the person conducting the assessment/making the diagnosis. The best and most accurate/valuable information will come from family/ staff/others who know the person well.

Without this, the process will be more difficult. Making the right diagnosis in a timely fashion can only be achieved when good quality, verified information has been gathered and is available for analysis/consideration. It is important that named staff and/or others who know the person well understand their responsibility to gather such information. It must be formally recorded and not just carried around in people's heads.

There is no clear consensus regarding the age at which initial symptoms may begin to develop or present. For people with Down Syndrome it is advisable to develop formal baseline assessments from the age of thirty five, if possible, in order to determine the person's pre-existing level of cognitive and memory abilities and adaptive functioning. This early screening will serve to aid any subsequent diagnosis of dementia in people with intellectual disability and particularly Down Syndrome.

Ultimately, information recorded such as health check information, reference to significant changes in the person's life and any psychological assessments conducted will enable the presence of dementia to be discounted or confirmed at the earliest possible point.

For the person with a diagnosis of dementia, or any long - term progressive illness, it is necessary to ensure there is a plan, reviewed on a regular basis, for the appropriate support. A component of the plan will involve the reflection of the person's rich life story.
Capturing the important information about the person is necessary to ensure that what the person needs to be well supported is known. It also ensures that the character, personality and loveliness of the person does not fade even though the illness advances.
The person with dementia is still a person first and much of what he/she was interested in and enjoyed in earlier times continues to be important.

While much will be already recorded in the person's Individual Plan, some areas to further consider and develop might include:

- What the person needs to be healthy, safe and well
- What gives him/her joy, happiness and contentment
- Who are the important people/loves in his/her life
- What is important to and for the person
- What others like, admire and appreciate about the person
- What are their intimate care and privacy needs
- What are their important life achievements, what makes them glow with pride
- What are their special gifts and qualities
- What are the person's hobbies and interests.

While some of the information recorded is likely remain fixed over time, other aspects should change. It is essential to update the necessary information on an ongoing basis to ensure it reflect the person's changing/evolving needs and circumstances.

Some Issues of Importance – Medical Treatments

Decision Making - Capacity and Consent – Person's Rights

People with intellectual disabilities commonly have greater health care needs than the general population. Yet, they typically have problems accessing health services. "People with intellectual disabilities are frequently not viewed by professionals within acute general hospitals as being a critical source of information. As such they are often not communicated with directly, not involved in discussions or decisions about their health care and are not asked directly to consent to examination, treatment and care" (Hart 1999, Hutchinson 2005, Barr 2004, MENCAP 2004).

Furthermore, if the person has behavioural difficulties they may avoid or infrequently use health services or their illness may be seen to be related to their learning difficulty and treatment may be delayed/declined. Combined, these factors could contribute to a poorer quality of life and outlook for the person.

As advocates it is necessary to support the person to access information which will help him/her to make informed decisions. In relation to medical matters, it is the doctor's role to assess capacity and communicate the information to the person themselves in simple terms though sometimes it may be necessary to translate the medical terms or support people through repetition of information, diagrams, pictures, easy to ready information for example. See intranet resources.

To demonstrate capacity we need to ascertain:

- Does the person understand in simple language what the proposed care and/or treatment is, its purpose and nature and why it is being proposed
- Can the person understand the main benefits, risks and possible alternatives and consequences of NOT receiving the proposed care/treatment
- Can the person retain the information for a sufficient period of time in order to consider it and arrive at a decision
- Does the person believe the information given
- Can the person repeat the information back in simple terms
- Can the person communicate the decision.

Remember:

- Assume capacity. All adults are presumed to have capacity unless and until they show otherwise
- Capacity refers to the ability to make a particular decision at a particular time
- Capacity must be present before consent can be given by the person
- Capacity can vary in the same person for different decisions and can fluctuate over time. The person's lack of capacity to give informed consent on one occasion is not assumed to hold true on another occasion.

The Medical Council Ethical Guide, issued to all doctors by the medical council, states that "if a person with a disability lacks the capacity to give consent, a wide-ranging consultation involving parents/guardians and appropriate carers should occur.

However, the decision ultimately rests with the medical practitioner. He/she will act in the best interests of the patient in making general medical decisions.

Staff has a responsibility, where capacity to make an important health related decision is at issue, to ensure the significant people in the person's life are included in consultations with the health care professionals.

The Ethical Guide does not expressly state what approach should be taken in the event of disagreement between doctor and family members. However, if there is disagreement a second opinion could be sought or another doctor asked to take over the case.

For further information, see intranet resources – "Medical Decisions" - Inclusion Ireland booklet.

The person has the right to choose what treatment is right for him/her. This includes refusing all conventional medical treatments and complementary therapies. Ensure the people who know and care about the person, those who form his/her circle of support, have been included in these discussions and are aware of the person's decision.

If the Person Needing Treatment is Very Worried and Anxious
Some people have a really difficult time setting foot inside a health care facility/hospital. They will refuse examination. It may manifest itself in acute anxiety with all its attending difficulties. It may be a fear of blood, injections, dental treatment, hospitals or separation from family, for instance. It may be connected to very bad earlier experiences.

Their anxiety reveals itself in an overpowering urge to escape from the situation that he/she is in. It can produce very unpleasant physical symptoms such as heart palpitations, dizziness, feeling sick, intense sweating, restricted or fuzzy hearing or sight, for example.

The best way to counter this anxiety and fear is to help the person to "de-condition" or desensitise. This is done by gradually exposing the person to the things they fear, and experiencing those fears without running away, and so becoming less sensitive to them.

Examples of desensitisation programmes might include some of the following:

Dentist anxiety – Show the person pictures of the dental surgery and staff. Befriend the dentist. Visit the dental surgery and sit in the waiting room, read magazines, chat with the receptionist. Get used to sitting in the dentists treatment room; Progress to sitting in the chair. Have a signal system arranged whereby the dentist promises to stop at the signal. (Some dentists even have a cut off switch on the equipment to allow the person to stop all work instantly.) Finding a way to help the person to control what is happening is important in this process.

Fear of hospitals – Figuring out what the person's main fear involves is the starting point. It may be a fear of injection, blood, injury or separation from loved ones. It may be something such as white coats or hospital smells or something very different.
Early steps might involve walking past the hospital, or sitting on a bench in its grounds. Walking through the hospital, working up to having tea in the canteen/coffee shop or sitting in a waiting room without any expectation or prospect of any medical intervention taking place may all be helpful measures. Bringing along precious possessions/favoured items e.g. music may help ease the anxiety for the person by giving them something to do. Sometimes the hardest progress is made in the smallest steps. Encourage the person to persevere and congratulate them every time they make progress.

Undertaking a desensitising approach requires knowledge of:

- What is the person anxious about?
- What can the person do now?
- What does the person want/hope to achieve?
- What steps are required to gradually expose the person to the source of their anxiety?

Where concern exists in relation to the person's anxiety levels, seek the support of Behaviour Support or Psychology via discussion, in the first instance, with the RSM.

Person's Safety, Rights and the use of Restrictive Practices

When the person attends healthcare facilities/hospitals he/she may be so worried and anxious, despite the really good preparatory work undertaken with the person that he/she behaves in a way that impacts their safety and the safety of others.

These situations vary in severity from a tendency to pull or pick at bandages and wounds, to more difficult and disruptive behaviour. In addition, the person's physical illness, discomfort or pain, side effects of medication, psychological stress et al can all contribute to the person's acute anxiety.

In crisis or emergency situations of extreme danger to the person or others, it is important to use common sense. As a last resort, when all other strategies have been explored and exhausted, the use of restrictive practices may be required.

Restrictive Practices – Guiding Principles and Safeguards

Restrictive practices may include any direct interference with the movement of the person by:

- Mechanical restraint
- Physical restraint
- Chemical restraint
- Environmental restraint.

Restrictive practices should only be used where a person poses an immediate threat of serious harm to self or others and must fall within the principles and parameters of the organisation's policy in relation to *"Listening and responding to people who challenge us and Restrictive practices"*.

The use of restrictive practices should only be considered as a last resort when all alternative interventions to manage the person's behaviours have been considered.

When opportunity presents, a multi-element assessment should be carried out, which looks at the reasons why the person is behaving as they are . This can include:

- Past assessments of the person
- Risk assessment and risk management plan for the person
- Physical illness, discomfort or pain; effects of drugs; psychological distress
- Environmental factors
- Staffing levels and the approach utilised by staff.

Family and people important to the person must be invited to participate and be included in decisions of such significance.

Any intervention employed affecting a person's liberty should be the least restrictive and safest intervention to manage the situation and should be in proportion to the risk posed.
The use of a restrictive practice should be used for as short a time as possible and must be reviewed at regular intervals to ensure due process.

The assessment should also attempt to predict and understand how the person is likely to feel if a restrictive practice is used. A person should not be restricted in a way that causes greater distress than the original problem.

Restrictive practices should never be used to ameliorate operational difficulties such as where there are staff shortages or defects in the environment.
(Extracts as reflected in HIQA, National Quality Standards: Residential Services for People with Disabilities)

If it is necessary to either hold someone's arm without their agreement, but with the agreement of their advocate or to hold someone's arm to take blood when the opportunity arises without their consent, then it should be considered a right's restriction. In both instances then the rights checklist should be completed and the issue should be reviewed by the Rights Review Committee (RRC).

Medication

Many people may be taking medication for a considerable time. The use of anticonvulsants for epilepsy and medication for hypothyroidism and diabetes, for example, are some of the long term medications some people may be taking. As people grow older additional drugs may also be prescribed and the combined effect of these can lead to serious side effects and health difficulties.

Medications need to be reviewed on a regular basis to avoid the unwanted side effects of drug interactions (Livingston 2003). Furthermore it is also important to be aware that changes in metabolism occur with ageing and that drugs that people may have tolerated well for some time may begin to have adverse side effects.

It is essential therefore that all people who support the person are aware of changes that may be the result of an increase in the number or type of medication being prescribed. It will be necessary to bring these to the notice of the medical practitioner involved with the person. See intranet resources for drug side effect information.

Psychotropic Medication – (Medication for the Control of Behaviour)
People who are prescribed psychotropic medication may experience severe side effects from these powerful medications. Providing the person/their advocate with information about all risk factors associated with these medications is very important if they are to make an informed decision. Any side effects noticed must be notified to the person's G.P at the earliest opportunity and to the psychiatrist at the next review. The person's psychotropic medication must be reviewed at least annually and tracked to gauge its effectiveness. The "Review Process for Psychotropic Medication" is especially helpful when preparing for such a review. See intranet resources.

If there are any questions or concerns related to the person's diagnosis, mental health condition, rights issues or their medication, it is important that the Named Staff and FLM discuss this with their RSM. The RSM will consult with BSS/Psychologist and decide if a referral to Psychiatry is considered appropriate.

When giving medication it is essential to follow pharmaceutical manufacturers' and clinical guidelines in tandem with the organisations *Medication Policy and Procedure*. Some tablet form medications, for example, should not be crushed or taken with other medications or foods. The crushing of medication can significantly alter its efficacy.

If a person is having difficulty accepting or swallowing particular medications it is necessary to consider alternative means of giving the medication, e.g. liquid form or transdermal patch.

If after exploring these options, the person still has difficulty swallowing their medicines, then administering it with food or drink may be an option. The idea of concealing medication may appear to be a ready solution to this difficulty.

However, the administration of covert medication to an autonomous individual contrary to his/her wishes is, legally and ethically, unacceptable. To do so would violate the person's autonomy and the core principal of consent. Refer to the organisation's *Medication Policy and Procedure* for very specific guidance in this respect.

Some aspects which must be considered and addressed:

- Does the person know what their medical condition is? What efforts have been made to inform them?
- What does the person know about their medication/treatments given? Do they know about the advantage and side effects of their mediation/treatment? Do they know the consequence for them if they decline medication/treatment?
- Has any effort been made to support the person to become involved in the administration of their medication?
- What is the person's preference for taking medication in different forms e.g. liquid, patch or tablet?
  (See intranet resources for support in this area)

In situations where voluntary acceptance of medication is difficult or impossible, it is necessary to ensure, in the interests of best practice, that the person's circle of support are involved in deciding how/if the medication will be administered.

A decision of such import requires the shared consideration of the person, health care personnel, family and staff who know the person well.

Refer also to the organisation's *Medication Policy and Procedure.*

Assistive Technology

At different stages throughout life we need aids, appliances and adaptations to enable us to live full and independent lives. We use assistive technology almost all of the time without really thinking about it, it is a routine part of our lives. It enables us to take advantage of a variety of experiences and activities and provides us with greater choice and control about what we will do and when. It also assists us to stay safe.

Assistive technology enables us to perform functions that might otherwise be difficult or impossible. It is any item, high or low tech, whether purchased off the shelf or customized which enhances our independence. A few examples include:

- Toilets and showers equipped with grab rails for people who may fall easily or require additional supports
- Communication aids/devices
- A computer that can be programmed to talk for an individual who can't speak
- Hearing aids and other amplification devices for people with hearing loss
- Mobility devices such as wheelchairs and walking aids
- Items with larger buttons such as telephone, remote controls or calculator
- Large screen computers for people with visual problems or touch screen for people who use touch to give commands
- Devices that operate lamps, radios, etc.
- Hoists and transfer boards.

Sometimes the best assistive technology solutions are no-tech or low-tech requiring little more than creative solution focused thinking. Some examples include the use of Velcro to stop items slipping, a timer to signal the passage of time or a piece of foam to enable a better grip.

When particular assistance is sought, a referral to the relative member of the assistive technology service is advised via Front Line Manager and RSM.

When an individual lives in a residential setting, typically a referral to Western Care Association, Senior Occupational Therapist, is required via the Front Line Manager and RSM. When an individual is living at home and needs some specialised adaptive equipment, the services of the community occupational therapist may be accessed via the person's GP.

Complementary Therapies

Complementary therapy is known by many different terms, including alternative therapy, alternative medicine, holistic therapy and traditional medicine. A wide range of treatments exist under the umbrella term of 'complementary therapy'.

Complementary therapies aim to treat the entire person, not just the symptoms. Some of the more popular complementary therapies include:

Acupuncture	Herbal medicine
Homeopathy	Alexander technique
Naturopathy	Aromatherapy
Chiropractic	Yoga
Osteopathy	Reflexology
Cranial Sacral Therapy	

Complementary therapies are widely used around the world. They are often based on traditional knowledge; this is why there is sometimes less scientific evidence available about their safety and effectiveness.

Natural and complementary medicines can be bought without prescription; however, they may have side effects or interact with other drugs, or they may not be the most effective treatment. It is necessary to let the health professionals know about all medicines – herbal and conventional – that the person is taking.

Conventional medicine and complementary therapies can often work well alongside each other. However, it is important to tell the doctor and complementary therapist of all drugs, treatments and remedies being taken. Herbs and homeopathic remedies can sometimes interact with prescription drugs and cause side effects. One must keep all health carers informed to ensure medicines are being used safely.

Never stop taking prescribed medications, or change the dose, without the knowledge and approval of your doctor.

Choosing whether or not to use a complimentary or alternative therapy is a personal decision.

In order to make a safe and informed decision, the following advice needs to be observed:

- As with conventional healthcare decisions, refer to the person and his/her circle of support if considering any complementary treatment options. Ensure the important people in the person's life are involved in any decision made.

- Provide the person with appropriate and accessible information about the proposed therapy so he/she may be enabled to make an informed decision. Include information on the possible benefits it may bring, how often it will occur and over what period, any possible interactions with other medications or side effects and how much it will cost him/her.

- Discuss the proposal with the person and their G.P/healthcare professional. Advice can then be provided based on the person's medical needs and this helps to ensure

co-ordinated and safe care. Some complementary and alternative approaches may interact with the person's current medication regime or exacerbate an existing medical condition. If the person is availing of an alternative or complementary therapy, it is important to give the doctors/healthcare providers a full picture of what the person does to manage his/her health. Include over the counter and prescription medicines as well as any dietary supplements etc. In this way any potential harm that could arise for the person may be identified before the complementary therapy proceeds.

- If considering an alternative therapy, in all circumstances, ask the person's GP about its safety, effectiveness and possible interactions with other medicines. The pharmacist is another additional source for this information. See also Medication Policy and Procedure.

- The G.P can recommend a complementary therapy practitioner if one is known and if deemed beneficial to the person.

- Contact a professional organisation/regulatory agency or licensing board to establish if the practitioner is recognised/listed. Ask about their training and qualifications.

- Monitor and evaluate the therapeutic intervention at regular intervals to ensure it is meeting the expected outcomes for the person. Maintain a record of the evaluations.

- **Be very cautious about any complementary therapy practitioner who advises you to abandon conventional medical treatment. <u>Always</u> follow the advice of the person's G.P/consultant.**

Resources

These resources are to be used when required and where they prove helpful.

Western Care Association Intranet. Click on AT – Personal Outcomes. Click on the icon/symbol with the caption "I have the Best Possible Health I Can". If you do not know the Intranet password, ask colleagues/Manager.

A range of resources will be revealed which are updated on an on-going basis. They are designed to make health information as accessible as possible for the person. Pictures and symbols are used in the main.

AT Section – Intranet – Best Possible Health –Content Overview

1. Promoting Health – Preventing Illness
2. Health Checks
3. Hepatitis B
4. Indicators of a Possible Underlying Health Problem
5. When Pain May be Present
6. Mental and Behavioural Health
7. Decline in Skills
8. Decision Making, Capacity and Consent
9. Safety, Rights and the Use of Restrictive Practices
10. Worried/Anxious about Treatment
11. Attending Hospital Appointments
12. Medication
13. Assistive Technology
14. Complementary Therapies
15. Resources.

Supporting the Person's Health – My Health Action Plan

Communication is a critical link in every healthcare interaction, whether it's making an appointment, describing symptoms, discussing risks and benefits of treatment or understanding treatment instructions. Communicating effectively with the healthcare provider will help one to make good decisions and follow the advice given which will aid better health outcomes and satisfaction for the person.

Keeping track of what needs to happen next for the person, informing people about changes in a health condition or keeping record of the outcome of appointments, which staff must maintain, requires a level of organisation.
To ensure the necessary discussion, planning, preparation and documentation of the person's healthcare needs takes place, staff must organise and reflect this information in the person's **Health Action Plan (See Appendix A).** The Health Action plan contains a number of forms that include:

- Nature of Health Issues/Long Term Conditions
- People the person sees about their health
- Medications person is taking
- Medical Appointment Forms to record what occurs at appointment
  Staff must track health appointments attended throughout the year.
- Health Action planning – what needs to happen, who will do that and when.

- The named staff should assist the person to stay informed about and access health checks that are consistent with their age and risk factors using checks available in **Appendix B -Preventative Health Care Checks**

- Staff must identify any tasks that need to happen having gathered all of the person's relevant health information. The **Health Action Plan** contains a form to use when recording what needs to happen, who will do it and by when.

- Staff must review, analyse and organise all relevant information in advance and bring it along to any medical appointment as it helps the healthcare provider make the best possible decision and recommendation with/for the person.

- Staff must track health appointments attended throughout the year. These can be recorded using forms available in the **Health Action Plan**. These keep track of appointments attended; identify where the decision/result is recorded and when the next appointment is due.

APPENDIX A

My Health Action Plan

My Health Issues / Long Term Conditions	Place to record: • What it is • How it affects me • Arising support needs
People I see about my Health.	Place to record: • Who I see • When I see them • Why I see them • Next appointment due.
My Medication	Place to record: • What I take • Why I take it • Side effects • Date for review
Medical Appointment Form	Place to record outcome of medical appointments
Planning Form	Place to record: • Issues identified • Tasks to do • By who and when • Date for review

MY HEALTH ACTION PLAN
My Health Issues/Long Term Conditions are:

Name: _____ **How I communicate:** _____

Date of Birth: _____ **Completed by:** _____ **Date:** _____

What is it? e.g. Bowel Difficulties, Ulcer, Gastric Problems, Epilepsy, Diabetes, Asthma.	How does this affect me?	My Support Needs
1.		
2.		
3.		
4.		
5.		
6.		
7.		

APPENDIX A

My Health Action Plan – People I see about My Health

Who I see	When I see them	Why I see them	Next appointment	Signed:

My Health Action Plan - My Medication

 **Medication**	**What is it for?**	**Side Effects**	**Date for Review**

MY HEALTH ACTION PLAN - MEDICAL APPOINTMENT FORM
CRITERIA FOR USE: ***RECORDING OUTCOMES OF MEDICAL APPOINTMENTS***
PERSON'S NAME: _____ DATE OF BIRTH: _____ ADDRESS: _____ _____
REASON FOR APPOINTMENT: _____ _____ _____
SEEN BY: _____
ACCOMPANIED BY: _____ DATE: _____
OUTCOMES: _____ _____ _____ _____ _____ _____ _____ _____ _____ _____ _____ _____ _____

NEXT REVIEW DATE: _____

My Health Action Plan – Planning Form

Health Issues Identified	Things to Do	By and When (Person to do things identified and timescale)	Review Date

Date of Reviewing Health Plan: _____

Reviewed by: _____

_____

Health Checks

Good health is achieved by not just reacting to ill health but proactively promoting health, preventing disease and helping people make healthy choices. This preventative approach to health care starts from the time we are born and should continue throughout our lives. The **health checklist** is a way of knowing what checks are due and how often they should be carried out.
To keep yourself healthy you should have regular health check-ups.

Preventative Care for Children and Adolescents
Throughout our childhood years, 0-18yrs, we undergo a range of health checks and immunisations. The frequency of these typically occurs at fixed intervals. They are reviewed periodically when new health care interventions are introduced and to amend an existing practice.

Preventative Care for Children and Adolescents

	Ages for Infants and Toddlers (age in months)	**Early Childhood** (age in Years)			**Middle and Late Childhood** (age in years)			**Adolescence** (age in Years)									
		3	4	5	6	8	10	11	12	13	14	15	16	17	18	19	20
Health Check Ups History, Height, Weight, Blood Pressure (starting at age 3) and other important assessments	At newborn, 2-4 days (if needed) 9-12 Months	→	Public Health Nurse		School Health Screenings												
Vision Test																	
Hearing Test																	
General Medical Check Up																	
Tuberculosis test (TB) Also recommended for children at higher risk											Recommend General Medical from 1 -3 Years Dependant on Risk Factors						
Dental Checks	Second and Sixth class at school – thereafter once a year.																
Rubella Vaccine	12 years or 5th/ 6th Class in National School																
HPV Vaccine (Cervical Cancer)	1st or 2nd Year in Secondary School																

APPENDIX B

Preventative Care for Young People with Down Syndrome

If the young person, 0-18 years, has Down Syndrome, there are additional health care considerations. The additional health checks require focus, most especially, on the areas of growth, heart, thyroid, sight and hearing. Particular attention must also be paid to the Axial - Atlanta joint difficulty which can affect some people. This condition can be identified by an X- ray. It is most important that medical advice is sought in relation to how best to support the individual to take part in activities safely.

DOWN SYNDROME MEDICAL MANAGEMENT GUIDELINES

	Growth	Heart	Thyroid	Sight	Hearing
Birth to 6 weeks	Length/weight/ head circumference – plot on Down Syndrome Specific Growth Charts*	Clinical Examination Echocardiogram 0-6 weeks **or** Clinical Examination ECG+Chest X-ray Birth **and** 6 weeks.	Routine Guthrie Test	Eye Examination, check for congenital cataract and glaucoma.	Neonatal screening where available.
6-10 months	Growth assessment as above at each routine visit*			Visual behaviour, check for squint.	Full audiological review (Otoscopy, Impedance, Hearing thresholds)
12 months	Growth assessment as above at each routine visit*	Dental Advice.	Full Thyroid function tests **or** TSH (finger prick)** yearly when available	Visual behaviour, check for squint.	
18-24 months	Growth (height/weight) assessment as above*	Dental Advice and Examination of teeth.	Full Thyroid function tests **or** TSH (finger prick)** yearly when available	Ophthalmological examination including Orthoptic screening, refraction and fundal examination.	Full audiological review as above.
3 - 3½ years	Growth (height/weight) assessment as above*	Dental Advice and Examination of teeth.	Full Thyroid function tests **or** TSH (finger prick)** yearly when available		Full audiological review as above.
4 - 4½ years	Growth (height/weight) assessment as above*	Dental Advice and Examination of teeth.	Full Thyroid function tests **or** TSH (finger prick)** yearly when available	Ophthalmological examination as above.	Full audiological review as above.

From age 5 years to 19 years

Paediatric Medical Review Annually

Cardiology Echo in early adult life to rule out mitral valve prolapse
Hearing 2 yearly Audiological review as above
Vision 2 yearly Ophthalmological examination including refraction and fundal exam
Thyroid 2 yearly from 5 years (venous) or TSH (finger prick) annually

Preventative Health Care for Adults

Health Check (18-39 years)

People aged 18-65 should have a full medical check every 1 to 3 years, depending on their health and risk factors.

	Description	Interval	Check
General Medical	• Blood Pressure Check • Height and Weight Check • Monitoring of side effects if on long term psychotropic drugs e.g. change in gait or mobility.	Every Year	
Medication Review	• Individuals on medication should have reviews for side effects and potential drug interactions/contraindications	Every six months or more often if required.	
Blood Tests	• Cholesterol. A baseline reading in your 20's	As recommended by your G.P.	
	• Diabetes. A blood glucose test to check for this if you have high blood pressure and high cholesterol. • Thyroid functioning test for people with Down Syndrome	Annually if you have high blood pressure/cholesterol, otherwise every five years. Every Year	
	• Liver Function.	Annually for people considered high risk.	
	• Hepatitis B.	Every three years for people at high risk	
Self-Examination	• Testicular and Breast Examination	Every month	
Screenings	• Cardio-vascular Screening	If deemed necessary	
	• Bone Density Screening. Start at 19 if risk factors present (long term poly pharmacy, mobility impairments, hypothyroid)	Periodically, following that as recommended by G.P.	
Cancer Screenings	• Smear Test	Every two years if sexually active and on advice from G.P. if not active.	
	• Mammogram	At 35, if you have a family history.	
	• Total skin examination	Every three years.	
Eye Tests	• General eye examination every two years or more for individuals with diabetes and syndromes associated with vision defects (Fragile X, Cornelia de Lang, Down etc.,) or for those on long term psychotropic drugs	Every two years or more for people considered in high risk category.	
	• Glaucoma Exam	Three to five years for individuals at high risk. Once for all others.	
Dental	• Every six months		
Hearing	• Every year	Annually	
Vaccines	• Flu vaccine	Annually, for those with diabetes or chronic medical conditions affecting the heart or respiratory system	
	• Pneumococcal vaccine	One dose to be given to an individual, considered high risk.	

APPENDIX B

Preventative Health Care for Adult

Health Check (40 – 59 years)

People aged 18-65 should have a full medical check every 1 to 3 years, depending on their health and risk factors.

	Description	Interval	Check
General Medical	• Blood Pressure Check • Height and Weight Check • Monitoring of side effects if on long term psychotropic drugs e.g. change in gait or mobility.	Every Year	
Medication Review	• Individuals on medication should have reviews for side effects and potential drug interactions/contraindications	Every six months or more often if required.	
Blood Tests	• Cholesterol.	As recommended by your G.P.	
	• Diabetes. A blood glucose test to check for this if you have high blood pressure and high cholesterol. • Thyroid functioning test for people with Down Syndrome	Annually if you have high blood pressure/cholesterol, otherwise every three years. Annually	
	• Liver Function.	Annually for people considered high risk.	
	• Hepatitis B.	Every three years for people at high risk	
Self-Examination	• Testicular and Breast Examination	Every month	
Screenings	• Cardio-vascular Screening	Annually if deemed necessary	
	• Bone Density Screening.	Annually	
Cancer Screenings	• Smear Test	Annually.	
	• Mammogram	Annually.	
	• Total skin examination	Annually.	
	• Prostate and Testicular screen	Annually.	
	• Bowel Cancer	Every two years.	
	• Colorectal Cancer	Faecal Occult blood test every year.	
Eye Tests	• General eye examination	Annually	
	• Glaucoma Exam	Every two years.	
	• Cataracts	Annually	
Dental	• Every six months		
Hearing	• Every year	Annually	
Vaccines	• Flu vaccine	Annually, for those with diabetes or chronic medical conditions affecting the heart or respiratory system	
	• Pneumococcal vaccine	One dose to be given to an individual considered high risk.	

APPENDIX B

Preventative Health Care for Adults

Health Check (60-64 years)

	Description	Interval	Check
General Medical	• Blood Pressure Check • Height and Weight Check • Monitoring of side effects if on long term psychotropic drugs e.g. change in gait or mobility.	Every Year	
Medication Review	• Individuals on medication should have reviews for side effects and potential drug interactions/contraindications	Every six months or more often if required.	
Blood Tests	• Cholesterol.	As recommended by your G.P.	
	• Diabetes. A blood glucose test to check for this if you have high blood pressure and high cholesterol. • Thyroid functioning test for people with Down Syndrome	Annually if you have high blood pressure/cholesterol, otherwise every three years. Annually	
	• Liver Function.	Annually for people considered high risk.	
	• Hepatitis B.	Every three years for people at high risk	
Self-Examination	• Testicular and Breast Examination	Every month	
Screenings	• Cardio-vascular Screening	Annually if deemed necessary	
	• Bone Density Screening.	Annually	
Cancer Screenings	• Smear Test	Annually.	
	• Mammogram	Annually.	
	• Total skin examination	Annually.	
	• Prostate and Testicular screen	Annually.	
	• Bowel Cancer	Every two years.	
	• Colorectal Cancer	Faecal Occult blood test every year.	
Eye Tests	• General eye examination	Annually	
	• Glaucoma Exam	Every two years.	
	• Cataracts	Annually	
Dental	• Every six months		
Hearing	• Every year	Annually	
Vaccines	• Flu vaccine	Annually, for those with diabetes or chronic medical conditions affecting the heart or respiratory system	
	• Pneumococcal vaccine	One dose to be given to an individual considered high risk.	

Preventative Health Care for Adults

Health Check (65 years and Older)

The person should have a full medical every year

	Description	Interval	Check
General Medical	• Blood Pressure Check • Height and Weight Check • Monitoring of side effects if on long term psychotropic drugs e.g. change in gait or mobility.	Every Year	
Medication Review	• Individuals on medication should have reviews for side effects and potential drug interactions/contraindications	Every six months or more often if required.	
Blood Tests	• Cholesterol.	As recommended by your G.P.	
	• Diabetes. A blood glucose test to check for this if you have high blood pressure and high cholesterol. • Thyroid functioning test for people with Down Syndrome	Annually if you have high blood pressure/cholesterol, otherwise every three years. Annually	
	• Liver Function.	Annually for people considered high risk.	
	• Hepatitis B.	Every three years for people at high risk	
Self-Examination	• Testicular and Breast Examination	Every month	
Screenings	• Cardio-vascular Screening	Annually if deemed necessary	
	• Bone Density Screening.	Annually	
Cancer Screenings	• Smear Test	Annually.	
	• Mammogram	Annually.	
	• Total skin examination	Annually.	
	• Prostate and Testicular screen	Annually.	
	• Bowel Cancer	Every two years.	
	• Colorectal Cancer	Faecal Occult blood test every year.	
Eye Tests	• General eye examination	Annually.	
	• Glaucoma Exam	Every two years.	
	• Cataracts	Annually	
Dental	• Every six months		
Hearing	• Every year		
Vaccines	• Flu vaccine	Annually, for those with diabetes or chronic medical conditions affecting the heart or respiratory system	
	• Pneumococcal vaccine	People considered high risk may receive vaccine prior to 65 and a second dose can be given if it has been five years since initial dose.	

Other Health Checks that May Benefit the Person

From time to time and depending on the person's health status and risk factors, additional health checks may be necessary. The guidelines under are to assist conversation/discussion with the G.P/healthcare professional.

Oral Health	• For people who do not have teeth, an examination by a dentist on an annual basis or as determined by the dentist.
Vision **Hearing**	• Screen for glaucoma at least once before the age of 40yrs and as recommended by the optician/ophthalmologist thereafter. • A person who is blind, examine at a frequency determined by the ophthalmologist. • Check for cataracts in people taking antipsychotic medication; ensure this is checked at least once a year or more often if advised. • People with diabetes or syndromes associated with vision abnormalities, have check-up promptly if change is noted. • Check for ear wax and have hearing checked if hearing problem reported or change in behaviour noted.
Immunisation	• Pneumococcal Vaccine, one dose to people over the age of 65, or earlier if at high risk, if advised by G.P. • Specific influenza virus vaccine e.g. Swine Flu H1N1 vaccine. Direction provided by G.P. • Hepatitis B – see Appendix A for further information.
Mobility	• Osteoporosis, bone density screening per risk factors of general population, Additional risk factors include long term medications, mobility impairment, hypothyroid. • Scoliosis, Spinal x-ray at intervals especially for people with particular syndromes. • Gait and Balance, check with G.P. if there is a change in gait or balance or if the person has had two or more falls in the previous year. Consider also if medications might be giving rise to the changes noted.
Medication Review	• Consider potential drug interactions/contraindications. Review medications and times of administration regularly.
Mental and Behavioural Health	• Depression – Consider if sleep, appetite disturbance, weight loss or general agitation are features of the person's state. • Memory loss – e.g. difficulty with names, verbal instruction, disorientation, difficulty performing familiar daily tasks.

Guidance Notes for Staff Members Supporting People to Attend Psychiatric & Neurologist Appointments:

1. It is very important that the staff member designated to support a person attending the above appointments would know the person well, and would be very well briefed before attending the appointment. Ensure all supporting documentation is taken to the appointment. (Consult the appropriate checklists contained in the attached Psychiatric & Neurologist appointment forms).

2. The role of the staff member is to support the person through the process of the appointment. Again it important that the staff member is aware of any anxieties the person may have about attending the appointment, and what strategies have been used at previous appointments to reduce and manage those anxieties.

   i. Ensure the person arrives on time and that the person has time to relax before going into the consultation room also ensure the receptionist is aware that the person has arrived for the appointment. The person may wish to use the toilet etc. prior to the consultation.

   ii. If a family member is attending the appointment, then the role of the staff member is to be an appropriate support to the person & the family.

   iii. Prior to the person & the family member going into the consulting room ask them whether they would like you to wait for them in the waiting area, or accompany them into the appointment.

   iv. During the consultation process the primary focus is the person attending & the family member. When introductions are being made the staff member should introduce themselves and clarify that they are there in a supportive role. The staff member should take the opportunity to hand-over the documentation that that they have brought to the appointment, and also to inform the psychiatrist that are happy to answer any questions or queries relating to the person.

   v. The staff member should contribute to the consultation when invited to do so by the psychiatrist.

   vi. Information presented must be clear & factual. Do not offer an opinion unless it is requested.

   vii. The staff member must present as a competent, supportive & professional person. The staff member is an employee of Western Care Association and must conduct themselves accordingly at all times.

   viii. At the conclusion of the consultation the staff member may if appropriate check if the person & the family member are clear about the decisions made at the appointment. This is also an opportunity for the staff to ask questions to clarify any outcomes from the consultation that they are not clear about. The purpose here is to enable accurate feedback to the person and later to the wider team supporting the person. Checking the date of the next planned appointment is also important.

   ix. The MA5 should be completed at the earliest opportunity after the consultation to ensure an accurate record of the consultation is captured.

PSYCHIATRIC APPOINTMENT FORM

Name of person: _____

D.O.B _____

How does the person communicate?

_____

Describe the person's current service/living arrangements:

_____

Why the person was originally referred to psychiatry?

_____

Factual report on how the person is presenting at present:

_____

_____

_____

Focus of current appointment: (Is *this a review or a new referral?)*

_____

GENERAL INFORMATION:

Mood?_____

Sleep?_____

Eating?_____

Energy levels?

_____

Any reduction in skill levels including self-care?

_____

List any current behavioural issues of concern?

_____
_____
_____

Has a hypothesis of the function or functions of the person's behaviour been formulated? If so describe:

_____
_____

Side Effects of Medication
If the person is being administered psychotropic medications; are they displaying any signs and symptoms of known side effects associated with the medication? If yes; list the signs and symptoms below:

_____
_____

INCIDENT DATA

How many behavioural incidents has the person been associated with since the last appointment?

Have incidents increased or decreased since the last appointment?

Has the severity and/or manageability of incidents changed since the last appointment?

How many of those incidents were at:

Severity level 3 ( )

Severity level 4 ( )

Severity level 5 ( )

How many incidents were at:

Manageability level 3 ( )

Manageability level 4 ( )

Manageability level 5 ( )

Present interventions in place:

Does the person have a current psychological assessment & report (Yes/No)?

Is there a behaviour support plan in place for the person (Yes/No)?

Is there a stress reduction plan in place for the person (Yes/No)?

Is there a PRMP and/or other support strategies in place for the person

(Yes/No)?

PRN **PSYCHOTROPIC MEDICATION**

Is the person prescribed PRN psychotropic medication
(Yes/No)?

If yes; how many administrations of PRN psychotropic medication has the person received since the last appointment with psychiatry
( )

Does the person have a PRN Protocol in place
(Yes/No)?
(*If there had been no administrations of PRN psychotropic medication in the previous 6 months, consider asking the opinion of the psychiatrist in relation to discontinuing the prescription*).

Is the person receiving any of the following supports:

Please tick appropriate box ☑

BSS □ Psychology □ O.T □ A.T □ S.L.T. □

OTHER (including other medical) _____

CHECKLIST:

- *Ensure the staff member supporting the person has been fully briefed about all relevant issues, and also how best to support the person before, during and after the consultation.*
- *The role of the staff member supporting the person is to present clear factual information when this is requested by the psychiatrist.*
- *Take white medicine sheet MP1*
- *Take current HONOS/DASS Assessments if available.*
- *Take behaviour recordings and/or incident data compiled since the previous appointment. A print-out of incident data from the service user data-base can be very useful.*
- *Take the relevant logs/recordings to the appointment.*
- *Take recent blood test results to the appointment.*
- *Take the results of any other diagnostic tests to the appointment*
- *Complete MA5 immediately after the appointment and send to RSM.*

LIST TARGET QUESTIONS TO ASK AT THE APPOINTMENT:
(*E.g. Does the medication prescribed have any side-effects or special precautions that the person/family/support staff needs to be aware of?)*

_____
_____
_____
_____
_____
_____
_____

Feedback from the appointment:

_____
_____
_____
_____
_____
_____
_____
_____

Neurologist Appointment Preparation Checklist:

NAME _____ D.O.B _____

NAME AND ADDRESS OF GP

_____

_____

_____

PRIOR TO APPOINTMENT

MEDICATION:

- Bring MP1 prescription sheet.
- Note when each medication was started, reviewed and why
- Note any vitamins and supplements been taken as they can interfere with anticonvulsant medication
- List previous epileptic medication, dosage, when it was stopped and why
- Bring actual medication containers with all tablets

_____

_____

_____

_____

RESULTS

- Note the results of all medical tests
- Bring results of MRI scan (brain and spine) CT, ECG and metabolic or genetic tests

BLOOD TESTS

- Ensure an up-to-date blood test is done and results are available for appointment.
  - Levels of different anti-convulsion medication
  - Liver and kidney function
  - Bone marrow
- Bring all blood test results
- Note any abnormalities in blood results

_____

_____

_____

_____

GENERAL INFORMATION:

- Collect information on the person's mood, sleep, eating, energy and Behaviour
- Bring behavioural, mood, sleep, and menstrual pattern recordings if applicable.

_____

_____

_____

_____

SEIZURE ACTIVITY

- Bring M10 epileptic seizure recording chart
  - When did first seizures occur?
  - How often do seizures occur?
  - How long do seizures last?
- When was the last seizure
- Describe a typical seizure
- How do you know a seizure has just happened e.g. person asks for a drink, goes to sleep etc.
- What is the protocol for when a person has a seizure e.g. administer diazepam
- How does the person seem after the seizure e.g. confused, sleepily
- Are there warning signs e.g. sensations, physical change
- What, if anything, seems to improve or worsen the seizures?
- Are seizures triggered by certain events or conditions?
- Was there unusual circumstances present e.g. very hot, stress, menstruation, mood swings, running, isolating themselves
- What was person doing leading up to seizure?
- Any changes in seizure pattern e.g. nature, time of day etc.
- Any recent life changes or stressors
- Know personal and family history e.g. does a family member have epilepsy, previous head injury, infections or tumours etc.

_____

_____

_____

_____

_____

_____

_____

INTERVENTIONS IN PLACE:

Bring the following if applicable

- Reports from other supports (if possible ask other supports to send a copy directly to Neurologist) e.g. Psychiatry □ Psychology □
- Reports from other medical consultants: name _____
- Reports from Day and Residential Services and home
- Healthy lifestyle plan

PREPARE TARGET QUESTIONS TO ASK AT THE APPOINTMENT:
For example

- What are the potential side-effects of the medication?
- Is there a possibility of an allergic reaction?
- What special precautions should the person/family/staff be aware of?
- Will anti-epileptic medication interfere with other medication or supplements the person takes? Or will other medication interfere with the anti-epileptic medication
- What is the treatment plan in relation to the Epilepsy?
- What do we do if a seizure occurs?
- How is the epilepsy affecting the person?

_____

_____

_____

_____

_____

_____

DURING APPONTMENT
Get the following information if possible

- Name of the registrar/consultant who spoke with you
- Name of the neurologist secretary
- Name of the clinical nurse
- Ask for clarification if you do not understand
- Jot down information during the appointment
- If problem arises after appointment and there is side effects from medication who do the service contact e.g. back up service

_____
_____
_____

_____

AFTER APPOINTMENT

- Make follow up appointments immediately
- Fill out M.A.5
- Inform relevant people of outcome e.g. circle of support, family etc.
- Fill any prescriptions
- Ask for medical report to be sent to family

PREPARATION CHECKLIST

☐ The lead staff member supporting the person is be fully briefed about all relevant issues.

☐ Up to date blood test results

☐ Up to date MP1 prescription sheet

☐ Up to date M10 epileptic seizure recording chart

☐ M.A.5 medical appointment form

☐ All past blood test results

☐ All relevant reports

- Period Service Review (PSR),
- Psychiatry information,
- medical consultants information,
- psychology reports,
- Reports from Day Centre, Residential home and family etc.

☐ Recording charts

- Behavioural,
- mood,
- sleep,
- menstrual pattern

☐ Records of all tests and results including MRI scan (brain and spine) CT, ECG and metabolic or genetic testing

☐ Medication containers with all tablets

☐ Medical card

☐ Appointment letter

Hepatitis B Immunisation

Hepatitis B is a viral infection that attacks the liver and can cause both acute and chronic disease. The virus is transmitted through contact with the blood or other body fluids of an infected person - not through casual contact.

Hepatitis B is a potentially life-threatening liver infection caused by the hepatitis B virus. It can cause chronic liver disease and puts people at high risk of cirrhosis of the liver and liver cancer.

Hepatitis B is preventable with a safe and effective vaccine.
A vaccine against Hepatitis B has been available since 1982. Hepatitis B vaccine is 95% effective in preventing HBV infection and its consequences, and is the first vaccine against a major human cancer.

As Hepatitis B is a significant cause of serious liver disease, the HSE recommend vaccine for people with an intellectual disability availing of day and residential services.

Western Care also recommends and offers vaccination to all people using its day and residential services. It is ultimately the decision of the person or their family to proceed or not with the vaccination process.

The Medical Card does not cover the cost of Hepatitis B vaccinations. Western Care will cover the cost of vaccination and/or blood testing.

Residential or Day Services will facilitate people (new and existing) who wish to avail of vaccination against Hepatitis B.

Basic Schedule

The basic schedule of Hepatitis B vaccination consists of a three dose course of vaccine, followed by a blood test to determine status of individual. The process is as follows:

1. Administer first vaccination dose
2. One months later – administer second vaccination dose
3. Six months later – administer third vaccination dose
4. Four months after the third vaccine dose, a blood test should be taken to determine immunity level: -

Blood test score	***Status***	***Action***
1-10 miu/ml	Non responder	• Full course to be repeated
10-99 miu/ml	Poor responder	• Booster shot required • Re-test at 2 - 4 months
100-1000 miu/ml	Adequate	• No further action required

Process for Day/Residential Services to follow:

The service will support the person to access the immunization programme, ideally through his/her GP. The service should be guided by the GP with regard to the number of times the process will be repeated to gain immunity.

Hepatitis B vaccination is part of the person's overall health check and as such, clear records should be maintained in the 'Best Possible Health Outcome' section of the IP file with copy of results to be also retained on Main File.

It is acknowledged that where the person lives with their Family/Guardian, there may be times when it is difficult to obtain results or maintain clear records. The Front Line Manager will seek to manage each situation as it arises: -

- Ensure all adults using services are being offered vaccination
- Ensure all children in Residential Services are being offered vaccination
- Record if the person refuses consent for vaccination
- Record stage of vaccination process and note when next stage is due
- Arrange appointment/visit with relevant GP for administration of appropriate vaccine or blood test at a place and time most suitable for the person
- Results to be retained on I.P. and copy sent to the Main File.

If the person consents to vaccination but then changes his/her mind at the time of vaccination, then that wish should be respected. Write to the person and/or family advising them of this situation and place copy of this letter on Main File.

Further Hep. B information may be sourced from the Front Line Manager and from the organisation.

Bibliography

- Medline Plus www.nlm.nih.gov/medlineplus
- Drugs.Com www.drugs.com
- Merck Manuals www.merck.com

British Institute of Learning Disabilities
Campion House, Green St., Kidderminster, Worcestershire, U.K.
www.bild.org.uk

Citizens Information
Citizens Information Board, Ground Floor, George's Quay House, 43 Townsend St, Dublin 2.
www.citizensinformation.ie

David Pitonyak,
3694 Mt. Tabor Rd., Blacksburg, Virginia, U.S.A.
www.dimagine.com

Disdat
St. Oswalds, Northumberland, Tyne and Wear. NHS Trust.
www.disdat.co.uk

Down Syndrome Association of Ireland
Citylink Business Park, Old Naas Rd., Dublin 12.
www.downsyndrome.ie

Health Service Executive.
Oak House, Milleneum Park, Naas, Co. Kildare.
www.hse.ie

HIQA
National Quality Standards: Residential Services for People with Disabilities
Unit 1301, City Gate, Mahon, Cork
www.hiqa.ie

Joseph Rowntree Foundation
The Homestead, 40 Water End, York YO306WQ, UK
www.jrf.org.uk

Inclusion Ireland
Unit 2, The Steelworks, Foley St., Dublin 2.
www.inclusionireland.ie

Massachusetts Dept of Developmental Services
Executive Office of Health and Human Services, One Ashburton Place, 11th Floor, Boston, Ma 02108
www.mass.gov

Mental Health Commission Code of Practice
Mental Health Commission, St. Martin's House, Waterloo Rd., Dublin 4.

www.mhcirl.ie

NCCAM national Institute of Health
9000 Rockville Pike, Bethesda, Maryland, 20892 U.S.A.
www.nccam.nih.gov

New South Wales Council for Intellectual Disability
418A Elizabeth Street, Surry Hills, NSW 2010, Australia
www.nswcid.org.au

The Council on Quality and Leadership
100 West rd., Suite 406, Towson, Maryland 21204, U.S.A.
www.thecouncil.org

Understanding Learning Disability and Dementia, Diana Kerr, 2007.

United Nations Convention on the Rights of People with Disabilities.
www.un.org/disabilities

Valuing People Now, Department of Health, U.K.
www.valuingpeople.gov.uk

World Health Organisation
Avenue Appia20, 1211 Geneva 27, Switzerland.
www.who.int