

Great Yarmouth and Waveney Joint Health Scrutiny Committee

Date: **Friday 16 January 2009**

Time: **2.30pm**

Venue: **The Kings Centre, Queen Annes Road,
Southtown, Great Yarmouth**

Persons attending the meeting are requested to turn off mobile phones.

Members of the public or interested parties who have indicated before the meeting that they wish to speak will, at the discretion of the Chairman, be given five minutes at the microphone. Others may ask to speak and this again is at the discretion of the Chairman.

Membership –

MEMBER

Mr M Cherry
Mr P Collecott
Mrs J Eells
Mrs J A Howe
Mr D Lockwood
Mrs S Vincent
Mr D Yorke Edwards
Mr B R Walker
Mrs S Weymouth

AUTHORITY

Suffolk County Council
Waveney District Council
Norfolk County Council
Norfolk County Council
Suffolk County Council
Forest Heath District Council
Suffolk County Council
Norfolk County Council
Great Yarmouth Borough Council

**For further details and general enquiries about this Agenda
please contact the Committee Administrator:**

Tim Shaw on 01603 222948
or email timothy.shaw@norfolk.gov.uk

1 To receive apologies and details of any substitute members attending

2 Glossary of Terms and Abbreviations

Terms and abbreviations used in the agenda papers. (Page)

3 Minutes

To confirm the minutes of the meeting of the Great Yarmouth and Waveney Joint Health and Scrutiny Committee held on 22 October 2008. (Page)

4 Members to Declare any Interests

Please indicate whether the interest is a personal one only or one which is prejudicial. A declaration of a personal interest should indicate the nature of the interest and the agenda item to which it relates. In the case of a personal interest, the member may speak and vote on the matter. Please note that if you are exempt from declaring a personal interest because it arises solely from your position on a body to which you were nominated by the County Council or a body exercising functions of a public nature (e.g. another local authority), you need only declare your interest if and when you intend to speak on a matter.

If a prejudicial interest is declared, the member should withdraw from the room whilst the matter is discussed unless members of the public are allowed to make representations, give evidence or answer questions about the matter, in which case you may attend the meeting for that purpose. You must immediately leave the room when you have finished or the meeting decides you have finished, if earlier. **These declarations apply to all those members present, whether the member is part of the meeting, attending to speak as a local member on an item or simply observing the meeting from the public seating area.**

5 To receive any items of business which the Chairman decides should be considered as a matter of urgency

6 Norfolk and Suffolk CFS/ME Service

Suggested approach from Keith Cogdell, Scrutiny Support Manager and reports by Mike Stonard, Chief Executive, NHS Great Yarmouth and Waveney and Tina Walton, Norfolk Local Involvement Network (Page)

7 NHS Great Yarmouth and Waveney's Five Year Plan

Suggested approach from Keith Cogdell, Scrutiny Support Manager (Page)

8 Agree Dates for Meetings in 2009

Members are asked to bring their diaries with them to the meeting (Page)

9 Forward Work Programme

To consider and agree the forward work programme (Page)

Chris Walton
Head of Democratic Services

Norfolk County Council
County Hall
Martineau Lane
Norwich
NR1 2DH

Chief Executive
Andrea Hill

Suffolk County Council
Endeavour House
8 Russell Road
Ipswich
Suffolk
IP1 2BX

Date Agenda Published: 8 January 2009



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Great Yarmouth and Waveney Joint Health Scrutiny Committee

Glossary of Terms and Abbreviations

ALTO	Arms Length Trading Organisation
BRAME	Blue Ribbon for Raising Awareness of ME
CBT	Cognitive Behavioural Therapy
CFS	Chronic Fatigue Syndrome
EAME	East Anglia ME Patient Partnership
EoESHA	East of England Strategic Health Authority
GET	Graded Exercise Therapy
ILSL	Improving Lives, Saving Lives
LTC	Long Term Conditions
ME	Myalgic Encephomyelitis
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NSF	National Service Framework
PBC	Practice Based Commissioning
PCT	Primary Care Trust
PRG	Patient Representative Group
RTT	Referral to Treatment
SDPG	Service Design Project Group
SHA	Strategic Health Authority
TTBT	'Towards the Best Together' (East of England Clinical Vision)
WCC	World Class Commissioning

Norfolk and Suffolk CFS/ME Services

Suggested approach from Keith Cogdell, Scrutiny Support Manager

1. Background

- 1.1 The issue of services for people with CFS/ME was referred to the Joint Committee by the Suffolk Health Scrutiny Committee in March 2008. Reports to the of the Joint Committee on 12 August highlighted past and current concerns of patient and carer groups about the level and nature of service provision, and clarified the arrangements for service commissioning and delivery.
- 1.2 The Joint Committee decided to focus its attention on work being undertaken by NHS Great Yarmouth and Waveney to revise the service specification, and how this fitted with the guidelines issued by the National Institute for Health and Clinical Excellence (NICE).
- 1.3 A report to the Committee on 22 October from the Chief Executive of NHS Great Yarmouth and Waveney described the approach being taken by the PCT in reviewing the service specification and linking this work to the NICE guidelines. The report also highlighted a delay in completing this work in respect of a key element of the NICE guidelines on 'Treatment and Management', and how this would be managed in respect of meeting deadlines for tendering for the services by April 2009.
- 1.4 The Chief Executive made a commitment that there would be no change to current services until the revised service specification and the tendering process with the new provider are completed.
- 1.5 The Committee agreed that a special meeting should be arranged to discuss the revised service specification. However, as can be seen from the annexed reports from NHS Great Yarmouth and Waveney and the Norfolk Local Involvement Network, work is continuing on this and the next meeting of the Service Design Project group has been scheduled for 9 January. Members will also have noted that the current service specification will continue to be used until the service re-design work has been completed and the revised specification has been agreed by the Trust's Board.

2. Suggested action

- 2.1 Given that it is not possible to pursue the original intention of today's meeting, it is suggested that Members:
 - Consider and comment on the contents of the annexed reports
 - Request a verbal update on progress made at the last Service Design Project Group meeting from NHS Great Yarmouth and Waveney and the

Norfolk Local Involvement Network

- Agree to revisit this subject when the revised service specification has been drawn up and before it is finally agreed by the Trust's Board



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Great Yarmouth and Waveney

CFS/ME Service Re-Design Briefing Note 8th December 2008

At the Great Yarmouth and Waveney Joint Health Scrutiny Committee meeting on 22nd October 2008, it was agreed that patient representatives would submit the final consensus view documents regarding a proposed service model by 31st October 2008. This was later extended to Monday 3rd November 2008. On this date, a consensus document was submitted for the following section:

- Treatment and management.

This document has been reviewed, and an early draft service specification has been prepared, which considers the views of patient representative members of the SDPG.

Work continues on the draft service specification. However, the next step is to reconvene a meeting of the SDPG to discuss this further. As the purpose of this meeting is to agree the draft service specification, it is important that all members of the group (both patient representatives and commissioners) are able to attend. Unfortunately it has proven difficult to identify a date prior to Christmas which is suitable for all attendees, and therefore the meeting will need to take place early in the New Year.

As members of the SDPG will be aware, NHS Great Yarmouth is required to formally establish its Provider Arm as an Arms-Length Trading Organisation (ALTO) by 1st April 2009 and will be tendering services provided by the Provider Arm. The services to be tendered include the CFS/ME Service. However, in recognition of the service re-design work underway with patient representatives and commissioners from other PCTs, together with the impending judicial review in February, it has been agreed that in the interim, the tender document will include the current service specification - this will ensure the continuation of a service in the interim, while NHS Great Yarmouth and Waveney commissioners continue to work with other commissioners, and patient representatives through the SDPG to develop a robust service specification.

Norfolk and Suffolk ME/CFS Service

Report by the Manager of Norfolk Local Involvement Network (LINK)

At the time of writing this report (6 January 2009), the new Service Specification has not been seen by Patient representatives or Norfolk LINK members (requests have been made). A meeting has been arranged for the 9th January to discuss the service model, Patient representatives, Commissioners and Norfolk LINK members have been invited to this meeting.

Update since 22nd October 2008 Joint Health Scrutiny Committee meeting.

Members of the Norfolk LINK have met with NHS Gt Yarmouth and Waveney representatives' Mr Michael Stonard (Chief Executive), Mr James Elliott (Commissioning Director) and Mr Alistair Lipp (Public Health Director), as recommended by the Gt. Yarmouth and Waveney Joint Health Scrutiny Committee. During the meeting it was stated that the Provider Arm of the PCT was struggling with staff shortages to provide an adequate service, and that discussions with commissioners at NHS Norfolk and Suffolk PCT were going to be held. The suggestion made by Mr. Stonard was to possibly approach Peterborough to provide an arms length service. Norfolk LINK has not been updated on the outcome of these discussions.

An email request for information has also been sent to the Provider Arm currently providing the ME/CFS service for information about the service they provide and at the time of writing this report a response has not been received. (The 20 working days deadline for requests for information is due on the 8 January due to bank holidays)

Patient representatives, in consultation with their groups, have completed and returned to NHS Gt. Yarmouth and Waveney the Treatment and Management section of the specification within 3 days of the deadline date 31st October 2008, in agreement with NHS GT Yarmouth and Waveney.

Further to Norfolk LINK discussions with NHS Gt. Yarmouth and Waveney, MP's Norman Lamb and Dr. Ian Gibson have met with a representative of NHS Norfolk and have requested a public meeting to be held to discuss the future of ME/CFS services in Norfolk.

I have also been in discussions with this representative of NHS Norfolk and informed him of the Joint Health Scrutiny Committee's meeting on this subject.

NHS Modernising agency – Good care planning for people with long term conditions

Every PCT is committed to achieving the maximum health improvement through prevention and other interventions ensuring that the primary care element of the targets of national service frameworks are met and comply with

quality requirements which also specify tertiary or secondary services. The National Service Framework (NSF) Long Term Neurological Conditions (LTNC) is specified with regard to children and young people. Patients and Carers recognise that NHS Gt. Yarmouth and Waveney's Board has chosen to provide all services under the NICE Guidelines. However, given that the guidelines for ME/CFS are under judicial review and the Trust is required to meet targets within the NSF, patients and carers are asking for the Trust to reconsider its decision and to consider the Long Term Neurological Conditions National Service Framework, as populated by the Peninsula School of Medicine. Patients are also requesting that the Trust considers an experienced consultant level (triage) and separate pathways for ME and CFS as they hold separate World Health Organisation (WHO) Identification Codes.

NSF Standard 7 – provision of appropriate specialist care

This standard demonstrated in a Best Practice Pathway demonstrates that access to a specialist CFS/ME team for advice should be available and that the team is multi-disciplinary and consists of a specialist consultant, specialist nurse, physiotherapist, occupational therapist (OT), dietician, counsellor, social worker, and links to other services.

The Specification for future services

Nationally, service users and carers are asking for a specialist consultant level Biomedical service to be instated and locally (see appendix 1) are requesting the new service specification to be led by a Biomedical Specialist in line with the National Service Framework (see appendix 2 NSF as applied by Peninsula Medical School). There is ever-increasing biomedical evidence to support an argument for this model both nationally and locally as can be seen by patient survey results; this model is that put forward by Dr Mitchell to the Department of Health in 2004 for a share of the £8.5 million investment in ME/CFS services based on the 2001 care pathway as outline by Mr. Mike Stonard at the 22nd October 2008 OSC meeting - "a care pathway had been introduced in 2001 and would continue in place until any change could be agreed with the patient groups". There is also overwhelming evidence through patient surveys nationally that Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT), treatments recommended by NICE, have only worked for 5% of patients surveyed. For the rest of the patients surveyed, these treatments have either made no difference or have worsened the patients condition.

Current services concerns

Patients and Carers are very concerned that the current inadequate service will continue to remain in place due to the delays, as recent meetings have been cancelled by NHS GT Yarmouth and Waveney in the development of the new Service Specification.

By NHS Gt. Yarmouth and Waveney's own admission, "there are staff shortages vacancies which cannot be filled". This is further compounded by the failure by commissioners to authorise replacement lead consultant posts. The current service is and has been for a long period of time, inadequate leaving patients undiagnosed, unmanaged and waiting to be seen longer than

the government waiting targets. Patients, carers and their families would like to see immediate action.



Suffolk Youth & Parent Support Group
for children, young people & young adults with long term medical needs

Appendix 1

Introduction

When the SDPG was set up it was emphasised that we are designing a service to meet local needs. With this in mind patient groups have carried out 2 surveys over the last 6 months gathering information from a total of 76 people with ME in Norfolk and Suffolk. In addition we have included information regarding NHS provision for children and young people

Patient Evidence A consists of 55 respondents and includes all patient groups from mildly to very severely affected.

Patient Evidence B comprises 21 respondents and was carried out in partnership with the 25% Group. This concentrated on the needs and experiences of those severely affected by ME.

Patient Evidence C comprises of information relating to children, young people and their carers from Cambridgeshire and Norfolk.

Patient Evidence A

An analysis of the information has been split into 3 sections:

- Background information, age, sex, severity of illness etc
- What the ME Service should provide
- Number and severity of symptoms

Background Information

1. On average people who responded have been ill for 11 years
2. The average age is 51, the youngest respondent is 15, and the oldest 80
3. 4 respondents are very severely affected, 24 severely affected, 23 moderately affected and 3 mildly affected
4. The average number of months waiting to be seen at the clinic is 5.3, the shortest time being 1 month and the longest 18 months
5. The most common precipitating factor is a combination of infection/trauma and trying to continue to work. This was the case for over half (51%) of respondents. This is an area where GP education could be very effectively targeted
6. A significant proportion, 30%, has not been referred to the ME Service at all, and for some of those that have been referred it has taken

months if not years to persuade their GP. This ties in with the fact that 25% do not have a supportive GP.

7. Dr Mitchell saw 46% of patients, Dr Gherkin 22%, GPwSI 22%, and OT's 11%. There have been some negative comments regarding GPwSI.

What should the ME Service Provide

1. 3 respondents answered 'yes' to every question and 5 respondents answered 'yes' to every question bar one.
2. 80% to 100% wanted the following:
 - ongoing support for their ME symptoms, advice on symptom management, monitoring of symptoms and medication and medical confirmation of symptoms and disability
 - a biomedical consultant
 - advice on pacing, an appropriate information pack
 - silent area/waiting room, home visits by consultant where necessary, consultant level monitoring of ongoing research with feedback to patients, opportunity to participate in research
 - blood tests, neurological tests, physical tests and a prescribing service.
 - mobility advice and advice on aids and equipment
 - ongoing support for secondary infections/diseases

Our evidence demonstrates that ME affects people for a long period of time and patients want ongoing support and monitoring provided by a biomedical service. It is likely that people want a prescribing service as they do not feel adequately supported by their GP. Medical confirmation of symptoms and disability is vital for people who are disabled by ME but have difficulty dealing with employers, insurers and claiming benefits.

3. The other results were less clear cut. 76% want counselling but only 33% a psychiatrist. People do not see themselves as having mental health problems but recognise counselling as a useful tool to assist in adjusting to chronic illness. There is a roughly even split between those who do and don't want CBT. 64% felt 8 weeks is an acceptable waiting time as long as the patient is referred quickly by the GP in the first place.

GET is the least popular intervention with 69% not wanting it.

Symptoms

1. Not every respondent recorded every symptom, and every respondent has multiple symptoms.
2. The most severe symptoms are post exertional fatigue, long recovery period from exertion, fatigue, sleep disturbance and pain. These are

the areas where intervention should be targeted. Medication for sleep disturbance and pain needs to be considered.

3. 100% of respondents are affected by fatigue, sleep disturbance, pain, sensitivities to light/noise, odours, memory disturbance and cognitive difficulties. Recording consultations and an information pack are a practical way that problems with cognition and memory can be ameliorated at clinic.
4. 90 to 100% are affected by post exertional fatigue, long recovery period after exertion, erratic body temperature, muscle weakness, and emotional lability.
5. 80 to 90% are affected by hot flushes, dizziness and weakness on standing, gastrointestinal difficulties, breathless with exertion, tender lymph nodes and recurrent flu like symptoms. Dietetic and nutritional advice is an area worth exploring. Difficulties in preparing meals and gastrointestinal problems can result in poorly nourished patients and so impede improvement. Medication for nausea can be helpful.
6. Overall the whole 'package' of symptoms has a significant affect on patients functioning and quality of life.

Patient Evidence B

This evidence relates to the severely affected and again has been split into 3 sections:

- Support received by patients
- What should the ME Service be offering for those who are severely affected
- An analysis of symptoms

Support received by patients

Nearly half, 48% receive no support at all from either their GP or the ME Service. 33% either have received or are in receipt of support from the ME Service. 29% receive support from GP's and 10% from social services etc. Some have received support from both GP and the ME Service which is why the total percentage is in excess of 100. Accessing services for people with severe ME is extremely difficult because of their physical limitation and disability and the special needs that they have, which are rarely provided for, such as a quiet room or a place to lie down.

What should a ME Service be providing for the Severely Affected?

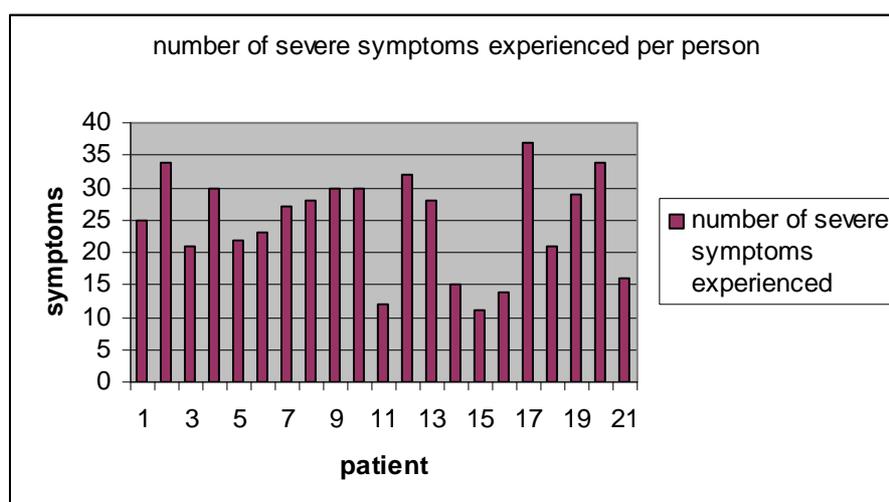
The results are very similar to the information gathered from Patient Evidence A.

1. 100% want a biomedical service, neurological and blood tests, symptom management, ongoing support for secondary infections and diseases, and medical confirmation of symptoms and disability.

2. 90 to 100% want physical tests, opportunity to participate in research, home visits/assessment by the consultant, short waiting time, silent waiting room, consultant level monitoring of ongoing research with feedback to patients, and an information pack.
3. 75 to 90% want a biomedical consultant, prescribing service, wheelchair and mobility advice, advice on pacing.
4. As with Patient Evidence A there is a recognition that help may be needed adjusting to chronic illness and 61% wanted counselling.
5. None of the respondents want a biopsychosocial service. 95% don't want a psychiatrist, 90% don't want GET, and 72% don't want CBT. Evidence from patients demonstrates that both GET and CBT to be inappropriate and harmful.

Analysis of Symptoms

1. The smallest number of symptoms experienced per sufferer is 12 and the maximum number of symptoms experienced is 37, the average number of symptoms experienced is 25.
2. The most severe symptoms are general malaise, post exertional fatigue, and loss of thermostatic stability
3. 80 – 90% experience head pain, bladder dysfunction, numbness, visual and perceptual disturbances, nausea and vomiting
4. 70 – 80% experience sore throat, flu like symptoms, heat/cold intolerance, extreme pallor, worsening of symptoms with stress and slow recovery and pain



Patient Evidence C

This patient evidence was collected from children, young people and their carers in Norfolk and Cambridgeshire. The evidence was presented to Dr David Vickers, who is Director of Specialist Children's Services, South Cambridgeshire PCT, and was on the NICE Working Group. The information was used to inform the development of children's services in Cambridgeshire.

Service Provision

1. GP Service

- a. As with adult services it is entirely a matter of chance as to whether an understanding GP is involved in the care of the child. Frequent examples of families changing GP practice in order to find someone sympathetic.
- b. GP's appear to be out of their depth in dealing with complex cases.
- c. Lots of examples of disbelief, sarcasm, accusations of neurotic mothers.

2. Community Paediatric Service

- a. Usually referred because of the need for out of school teaching rather than the CPS having any particular specialist knowledge of ME.
- b. Knowledge and understanding very patchy resulting in overambitious expectations by HCP's.
- c. Lack of continuity of care and regular review appointments
- d. Some paediatricians willing to do home visits which was welcomed

3. Mental Health Services

- a. Arrogance verging on abusive, lack of understanding and knowledge among HCP's
- b. CBT did not result in recovery, though counselling did help children adjust
- c. Too willing to diagnose depression and where present depression was as a result of the way children have been treated by Teachers and HCP's rather than as a result of the effects of ME

Overview of NHS Services

1. Doctors generally very patronising and parents do not feel listened to.
2. Paediatricians not found to be very good at talking to or relating to children
3. Lack of provision of written information for children and parents to refer to
4. Lack of appropriate management early on leads to deterioration

5. Lack of parental involvement and choice, referrals to other HCP's without consent
6. Lack of co-ordination and communication between HCP's
7. CMO's Report published in 2002 does not appear to have made any difference to the experience of service users

NHS and LEA

1. No evidence of joined up working, some described the situation in Cambridgeshire as 'appalling'.
2. Situation somewhat better in Norfolk where long term provision for children is recognised and provided
3. Many children put under pressure to return to school when unfit, and inappropriate demands of schools thought to do a great deal of damage to children

Suggested Improvements

1. Education of doctors and other HCP's so they are up to date with research into ME and management and treatment of the illness.
2. Education of LEA's so that children are not pressured to do longer hours at school, return to school before they are ready, and easy access to home tutoring.
3. Willingness to listen to parents and children's experiences, and to take into account the sometimes profound functional disability and disruption to family life as a result of ME.
4. HCP's should communicate effectively and agree an individualised management strategy for each child.
5. A genuine choice of management approaches should be available as with other illnesses.
6. There is a need for domiciliary and acute services.
7. ME is a chronic illness. Long term support is vital.
8. It is more important that HCP's knowledgeable in the field of ME are provided than a specialist children's service per se. One respondent commented that she would rather her child saw a specialist in ME than a paediatrician with little, no or inappropriate knowledge in the field.

Conclusion

As our surveys have shown, ME sufferers in Norfolk and Suffolk want the ME Service to¹:

Honour the fact that ME is a serious neurological disease (WHO ICD 10. G93).

- Acknowledge that 'Myalgic Encephalomyelitis' is a World Health Organisation (WHO: ICD 10 - G93.3) defined neurological disease and is not the same condition as 'idiopathic chronic fatigue' described separately by the WHO at ICD -10-F.48.

- Use an appropriate biomedical definition that takes account of the above and accords with international research evidence, expertise and proper WHO illness category demarcation.
- Actively educate other clinicians, paramedical staff and social and child-education services regarding the true physical nature and impact of this disease.
- Use the primary WHO-listed name "Myalgic Encephalomyelitis", as opposed to "CFS, Chronic Fatigue or Encephalopathy" (Hooper 2007)

Respect the fact that ME is a multi-system disease affecting all systems of the body:

- Acknowledge that biopsychosocial CBT/GET treatments are deemed inappropriate at best and contra-indicated at worst by leading international specialists and consensus diagnostic and treatment protocols ⁱⁱ ⁱⁱⁱ
- Be particularly aware of the severity of severe ME symptoms and the high level of post exertional malaise and post- exertional fatigue experience and accommodate it; so that patients can be seen and given proper ongoing support.

Validate the ME sufferer's experience through adequate biomedical testing:

- Provide a biomedical clinician who can recognise the symptoms of real ME, their impact, and make appropriate recommendations, based on current physical research and state-of the-art practice.
- Offer appropriate biomedical tests and scans that prove that the severe ME sufferer has a physical illness and illuminates what is going wrong in their body.
- Provide appropriate state-of the-art biomedical assessment that will provide a medically-informed and scientifically objective report about the illness and disability.
- Give patients the opportunity to choose to participate in physical research, especially the severely affected that have in the past been excluded and/or underrepresented in research projects. It is hoped that this will promote better patient outcomes and disease prevention.

Treat the symptoms as much as possible:

- Explore, prioritise and validate the neurological symptoms of ME.

- Provide home visits from a biomedical clinician for those not well enough to travel.
- Have the willingness and funding to prescribe drug and nutritional interventions for illness management (e.g. pain relief and sleep promotion) and, where possible, for better prognosis (e.g. appropriate antiviral treatments).
- Acknowledge that all other treatments/therapies should be agreed with the input and agreement of the ME specialists as principal advisors - due to their understanding of possible adverse reactions, complications etc. This particularly applies if there are also mental health/ conditions/complications.

Competently provide support:

- Acknowledge the genuine severe disability so that support can be given to sufferers to claim benefits and grants etc, to enable true entitlement.
- Offer advice based on awareness of safe practice and safe treatments regarding how to deal with other medical conditions and illnesses that might arise.
- Provide access by phone for specific symptom management/ backup.

Appendix 2

Illustration: NSF for Long-Term Conditions - as applied to CFS/ME As taken from page 24 of the Peninsula Medical School – Service Investment Programme Report 2004-2006.

Quality requirement 1: A person-centred service

People with CFS/ME are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.

Quality requirement 2: Early recognition, prompt diagnosis and treatment

People suspected of having CFS/ME are to have prompt access to specialist expertise for an accurate diagnosis and treatment as close to home as possible.

Quality requirement 3: Emergency and acute management

People with CFS/ME needing hospital admission for this or other health needs are to be assessed and treated in a timely manner by teams with the appropriate skills and facilities, seeking specialist advice regarding their CFS/ME, if needed.

Quality requirement 4: Early and specialist rehabilitation

People with CFS/ME who would benefit from rehabilitation are to receive timely, ongoing, high quality rehabilitation services in hospital or other specialist setting to meet their continuing and changing needs. When ready, they are to receive the help they need to return home for ongoing community rehabilitation and support.

Quality requirement 5: Community rehabilitation and support

People with CFS/ME living at home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.

Quality requirement 6: Vocational rehabilitation

People with CFS/ME are to have access to appropriate vocational assessment, rehabilitation and ongoing support to enable them to find, regain or remain in work and access other occupational and educational opportunities.

Quality requirement 7: Providing equipment and accommodation

People with CFS/ME are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently; help them with their care; maintain their health and improve their quality of life.

Quality requirement 8: Providing personal care and support

Health and social care services work together to provide care and support to enable people with CFS/ME to achieve maximum choice about living independently at home.

Quality requirement 9: Palliative care

People with very severe CFS/ME are to receive appropriate services when they need them to control symptoms, offer pain relief and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.

Quality requirement 10: Supporting family and carers

Carers of people with CFS/ME are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.

Quality requirement 11: Caring for people CFS/ME in hospital or other health and social care settings

People with CFS/ME are to have their specific needs met while receiving care for other reasons in any health or social care setting.

NHS Great Yarmouth and Waveney's Five Year Plan

Suggested approach from Keith Cogdell, Scrutiny Support Manager

1. Background

- 1.1 At its meeting on 2 April 2008, the Joint Committee received a report and presentation from Mike Stonard and Bernard Williamson, Chief Executive and Chairman of NHS Great Yarmouth and Waveney, on the outcome of the Trust's public consultation on '*A healthier future: Developing healthcare for Great Yarmouth and Waveney 2008 and beyond*', which had been conducted from 1 July to 30 September 2007.
- 1.2 Whilst the Joint Committee was content with the analysis of the responses to the consultation exercise, and with the way the outcomes had been used to inform service developments in the area, it wished to be updated on the outcomes of the current business plan and to learn how the findings from the consultation were to be incorporated into the PCT's five-year strategic plan. The Joint Committee therefore added the following to its Forward work Programme for its meeting on 22 October 2008.
- 1.3 On 6 October, Mr Stonard signalled his intention to present this item by means of a PowerPoint presentation, copies of which would be made available on the day. The reason for this was that the five-year strategic plan was scheduled to be discussed by the PCT's Board on 22 October, following the meeting of the Joint Committee. Mr Stonard therefore believed that it would be more productive for the Joint Committee to receive the document after it had been considered by the Board to enable a full discussion to take place.
- 1.4 In the event, Mr Stonard had to leave the Committee's meeting before this item could be dealt with. Members of the Committee therefore requested that they be given another opportunity to consider this matter before a final decision is taken by the Trust's Board, which is scheduled for 26 January.

2. Suggested action

- 2.1 It is suggested that Members of the Committee consider the contents of the presentation from Mr Stonard, seek clarification of any issues that seem unclear, and agree with NHS Great Yarmouth and Waveney any matters arising from the Five Year Plan that should be referred to the Committee in the future.



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Great Yarmouth and Waveney Joint Health Scrutiny Committee

ACTION REQUIRED

Members are asked to suggest issues for the forward work programme that they would like to bring to the committee's attention.

- consider whether there are topics to be added or deleted;
- consider and agree the briefings, scrutiny topics and dates below.

Please consider issues of priority, practicality and potential outcomes you wish to achieve before adding to the work programme.

Proposed Forward Work Programme

<i>Meeting dates</i>	<i>Briefings/Main scrutiny topic/initial review of topics/follow-ups</i>	<i>Administrative business</i>
6 February 2009	Changes to Older People's Mental Health Services in the NHS Great Yarmouth and Waveney area	
Mid 2009	Dentistry Services – requested at meeting on 12.8.08. Report by Elaine Bond, Head of Contracting, to include details of dental services for the disabled, hospital patients and those people who require a specialist home visiting service.	

Provisional dates for update reports to the Committee - 2009

October 2009 – **Older People's Mental Health Services in the Great Yarmouth and Waveney PCT area** – a full review of the outcomes of the changes that were subject to a public consultation from October to December 2007.