

Report to: **Adult Social Care and Community Safety Scrutiny Committee**  
Date: **14 June 2012**  
By: **Chairman of the Review Board**  
Title of report: **Scrutiny review: Dementia – caring for people with challenging needs**  
Purpose of report: **To present the outcomes of the scrutiny review.**

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**RECOMMENDATION: that the Committee considers the report of the Review Board and makes recommendations to Cabinet for comment and County Council for approval.**

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## **1. Financial Appraisal**

1.1 There are no direct financial implications from the report as recommendations are intended to be achieved within existing budgets.

## **2. Summary**

2.1 This review arose from discussion of Care Quality Commission (CQC) inspections of Adult Social Care directly provided services at Committee meetings on 8 September and 27 October 2011. During these discussions it was identified that there appears to be a lack of capacity and/or capability in the independent sector to provide residential care for people with challenging needs and behaviours due to dementia. The need for a review, focusing on care provision for people with challenging needs arising from dementia, was identified as a result.

2.2 The review assessed the capacity and capability of care homes and homecare services to provide effective care for people who develop challenging behaviour due to dementia. It considered four themes:

- the current and potential future demand for care for people with behaviour that challenges;
- the capacity and capability of homecare services to manage challenging needs effectively, particularly how health and social care services work together;
- the capacity and capability of the independent sector care homes to provide care for these clients now and in the future, and how this could be developed; and
- further best practice in relation to care for this group of people in our community.

2.3 The report attached at appendix 1 contains a summary of work of the Review Board, together with the findings and recommendations. The Committee is recommended to receive the Review Board's report for submission to Cabinet on 3 July 2012 and County Council on 20 July 2012.

COUNCILLOR PETER PRAGNELL  
Chairman of Review Board

Contact Officer: Claire Lee                      Tel No. 01273 481327

Local Members:                      All

Background Documents: None



# Dementia – Caring for People with Challenging Needs Scrutiny Review

## Report by the Project Board

Councillor Peter Pragnell (Chairman)

Councillor John Barnes

Councillor Pat Ost

June 2012

**Adult Social Care and Community Safety Scrutiny Committee – 14 June 2012**

Cabinet – 3 July 2012

Full Council – 20 July 2012



# The report of the Dementia – Caring for People with Challenging Needs - Scrutiny Review

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## Recommendations

Recommendation	
1	<p>To endorse the implementation of the recommendations from the Adult Social Care report: <i>Framework homecare providers and the care of people with dementia – a report on the current position with regard to specialist training</i>, which envisage a stepped approach to upskilling homecare providers in relation to dementia:</p> <ul style="list-style-type: none"> <li>• by actively promoting training to independent sector providers (initially managers);</li> <li>• by co-producing action plans with providers to embed the nationally recognised ‘Common core principles for supporting people with dementia’; and</li> <li>• by proposing changes to future contract specifications that will require providers to have achieved specific targets.</li> </ul>
2	An evaluation of the Carer’s Breaks Dementia Service should be undertaken, to encompass the wider roles that have been developed by the service.
3	The Adult Social Care and Community Safety Scrutiny Committee should consider the evaluation of the Continuous Improvement Strategy for Dementia Care Homes project in order to identify further actions required to develop practice.
4	Adult Social Care should examine all potential avenues to encourage or incentivise care homes to continue to develop the skills of their staff in relation to dementia.
5	The evaluation of the impact of the Care Home In-Reach Service should be reported to the Scrutiny Committee for consideration.
6	East Sussex County Council and the Alzheimer’s Society should consider whether there are opportunities to better co-ordinate their training packages.
7	Consideration should be given to the potential benefits and resource implications of applying for “dementia friendly community” status for East Sussex or specific local communities.
8	The County Council should develop the proposed website dementia information ‘hub’ to support increased community awareness and availability of information to care providers.

## Overview

1. The aim of this review was to assess the capacity and capability of homecare services and care homes to provide effective care for people who develop challenging behaviour due to dementia.
2. Previous discussion by the Adult Social Care and Community Safety Scrutiny Committee identified:
  - an apparent lack of capacity and capability; and
  - instances of failed care home placements where clients had subsequently been transferred to East Sussex County Council's directly provided services, which increasingly provide care for those with the most complex needs.
3. The review considered four themes:
  - the current and potential future demand for care for people with behaviour that challenges;
  - the capacity and capability of homecare services to manage challenging behaviour effectively, particularly how health and social care services work together;
  - the capacity and capability of independent sector care homes to provide care for these clients and how this could be developed; and
  - best practice in relation to community awareness of people with dementia and challenging behaviour.
4. The majority of people with dementia, particularly those in the earlier stages of the syndrome, do not have behaviour that challenges. However, challenging behaviours may occur at any stage of the disease and do eventually occur in most people with dementia.

## Areas outside the scope of the review

5. The following areas were not included in the scope of the review:
  - Improving dementia diagnosis- The Health Overview and Scrutiny Committee recently examined the development of a memory assessment service to increase rates of diagnosis.
  - The Age Well programme- We wished to avoid duplicating the work of this programme. Age Well should provide a number of residential places for people with challenging behaviour over the next two to five years.

# 1. The current and potential future demand for care for people with behaviour that challenges

## Dementia and behaviour that challenges

6. The term 'dementia' is used to describe a syndrome in which there is a progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, which complicate care and which can occur at any stage of the illness. Aggressive behaviour can be a response to an underlying issue such as pain, fear or frustration, or can be linked to the physical impact of the condition itself. There is a wide range of patterns of behaviour that challenges and these are often very individual and require a tailored response.

7. The National Institute for Health and Clinical Excellence (NICE) and Social Care Institute for Excellence (SCIE) state "behaviour that challenges may include aggression, agitation, wandering, hoarding, sexual disinhibition, apathy and disruptive vocal activity such as shouting".

8. More than half of all people with dementia experience challenging behaviour. People with behavioural and psychological symptoms of dementia are more likely to be placed in a care home.

9. A number of illnesses cause dementia, the most common being Alzheimer's disease, which is prevalent in 62% of dementia patients in East Sussex. A further 17% of dementia patients have Vascular Dementia and the remainder of patients have Dementia with Lewy Bodies, Fronto-temporal dementia, Parkinson's, a mix of illnesses or the classification 'other'. Some patterns of behaviour are more prevalent with certain types of dementia and treatments may have to be tailored to meet these differing needs. The cause of dementia was not a focus of this review, which concentrates on the social care needs of a person with dementia.

## Prevalence of dementia

10. The number of people with dementia in East Sussex is expected to increase substantially over the next 10 years. Latest estimates suggest a 20% increase from around 9600 in 2009/10 to approximately 11,500 by 2018/19.

11. Nationally, of the population with dementia, 55% have a mild form of the disease, 32% a moderate form and 13% a severe form. Around two-thirds of people with dementia live in the community and one third live in care homes. It is estimated that two-thirds of people living in care homes have dementia.

12. Diagnosis of dementia is increasing. In 2011, East Sussex Downs and Weald Primary Care Trust (PCT) diagnosed 35.7% of the estimated number of people with dementia whilst Hastings and Rother PCT diagnosed 41.7%. A new memory assessment service comes online from the autumn of 2012 which should significantly increase the rates of diagnosis in East Sussex. The Alzheimer's Society has recommended target diagnosis rates of two thirds by 2015 and three quarters by 2017. However, actual future diagnosis rates are difficult to predict.



## Trends in dementia care

13. The focus of social care policy is increasingly on helping those with lower level needs to remain in their own home. Consequently, it is likely that the proportion of people in care homes with more severe dementia will continue to rise. There is evidence that most care homes (including those not designated as Elderly Mentally Infirm (EMI)) have clients with dementia, although in many cases it will be undiagnosed.

14. The Department of Health has highlighted the requirement to reduce the use of antipsychotic medication to treat behavioural disturbances. This is in line with NICE's guidelines that advocate a non-drug approach to managing challenging behaviours based on individual assessment of needs. Medication is only to be considered, *"if there is severe distress or an immediate risk of harm to the person with dementia or others"*.

15. Early diagnosis is important in addressing and managing challenging behaviour as it enables appropriate support to be put in place, care plans to be developed and carers to be offered support. The investment in East Sussex in diagnosis and subsequent referral to a dementia advisor will increasingly offer advice and information to all those diagnosed at an earlier stage.

## Future demand

16. With an ageing population, the need for further capacity for dementia care in East Sussex is crystal clear. In particular, the need to increase the number of EMI nursing and care homes has been identified. Adult Social Care has recently produced a market position statement that clearly highlights these gaps in EMI provision. There is anticipation that this clarity will support and stimulate the market to develop additional provision in the future.

17. Adult Social Care will be commissioning an updated needs analysis for carers that will include an assessment of the future needs of carers of people with dementia.

## 2. The capacity and capability of homecare services

18. The Council commissions most of its homecare services through a framework agreement with the independent sector and directly operates two specialist services that are involved with the care of clients with dementia living at home, the Carer's Break Dementia Service and the Older People's Mental Health Team. The latter team works closely with the Community Mental Health Teams of Sussex Partnership NHS Foundation Trust.

19. People with the most challenging behaviours due to dementia are likely to be admitted to care homes, making it rare that homecare providers would encounter this level of need. However, it is important that homecare and other health and social care support provided to people who remain in their own homes (and their carers) is as effective as possible in order to delay the need for admission to a care home for as long as possible and to maximise quality of life. This includes responding to emerging or moderate behaviour that challenges in an appropriate way.

20. Adult Social Care recently completed a review of the level of dementia care training amongst the homecare provider workforce. This identified that there is currently a lack of specialist dementia training amongst staff at all levels. There is also a tendency for providers to upskill staff using e-learning or other self-study methods, rather than using the freely available Adult Social Care training, which encourages reflective practice using highly interactive methods, but has relatively low uptake. Due to the increasingly mainstream nature of dementia, it was concluded that upskilling all generic homecare staff is preferable to commissioning a specialist care team.

21. We consider that the recommendations of the report will develop the capacity and capability of the sector to respond to:

- the increasing prevalence of dementia in the county; and
- the increased complexity of need as more people with dementia are supported at home for longer.

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### Recommendation 1

**To endorse the implementation of the recommendations from the Adult Social Care report: *Framework homecare providers and the care of people with dementia – a report on the current position with regard to specialist training*, which envisage a stepped approach to upskilling homecare providers in relation to dementia:**

- **by actively promoting training to independent sector providers (initially managers);**
- **by co-producing action plans with providers to embed the nationally recognised 'Common core principles for supporting people with dementia'; and**
- **by proposing changes to future contract specifications that will require providers to have achieved specific targets.**

## **Carer's Breaks Dementia Service**

22. The Carer's Breaks Dementia Service, co-funded by East Sussex PCTs and Adult Social Care, offers respite for the carers of people with moderate or severe dementia. Referrals to the team come from either the Older People's Mental Health Team or the Community Mental Health teams of Sussex Partnership NHS Foundation Trust.

23. The team's main remit is to offer carers short breaks of 2 ½ hours during which they engage the carer and the client with peer groups and day centres. However, the team offers a range of additional services:

- training for drivers/escorts for the North Wealden Transport Service;
- client forums that create lists of places the clients enjoy visiting and which welcome people with dementia;
- dementia care training to independent sector homecare providers and voluntary sector organisations which involves the organisation/provider working directly with the team;
- training to community volunteers; and
- supporting handovers to care homes, including advice and education to staff on people's individual needs.

24. We were particularly interested in the support provided to carers and homecare providers in developing appropriate care plans, techniques and routines that assist in the management of any challenging behaviours. The knowledge of individual needs developed by the team, in conjunction with the carer, is also a valuable source of information to care home managers if a client is transferring to their care home, either temporarily or permanently.

25. As the team has embraced its role, it appears to have extended beyond its original remit. It is defined as a carers' service rather than a dementia service, although aspects of its wider roles could be viewed as support to the cared-for person. Further evaluation of the wider work undertaken by the service would be required to provide an evidence base to underpin any expansion of this support. Anecdotally, the support provided by the team has contributed to clients being able to remain at home for longer than would otherwise be the case and to settle more effectively into care home placements. It would be helpful to evaluate the work of the team more robustly to inform its future direction and any potential expansion in light of increased demand.

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### **Recommendation 2**

**An evaluation of the Carer's Breaks Dementia Service should be undertaken, to encompass the wider roles that have been developed by the service.**

### 3. The capacity and capability of care homes

26. Adult Social Care commissions the majority of its care home placements from the independent sector. This includes Elderly and Mentally Infirm (EMI) registered care homes that are designed to care for people with dementia, whose needs may include behaviour that challenges. The department, with its health partners, has recognised the need to develop the capacity of both EMI and non-EMI care homes to effectively support residents with dementia, which includes managing challenging behaviours without the unnecessary use of antipsychotic medication.

#### Continuous Improvement Strategy for Dementia Care Homes

27. Adult Social Care has recently completed a six-month '*Continuous Improvement Strategy for Dementia Care Homes*' project which was initiated in response to a rise in safeguarding activity related to EMI care homes over an 18 month period. Care homes have engaged positively with the project and welcomed the offer of additional support to develop their practice. The project has produced a Good Practice Guide, alongside a supporting framework that includes training and monitoring.

28. EMI care home managers and owners are the main target audience of the guide, as safeguarding issues tend to be the result of institutional shortcomings. The guide aims to support change in the culture of institutions over time.

29. The project also aims to encourage non-EMI providers to use the guide to improve their service, as most will have clients with dementia. A secondary benefit of the project could be to encourage more care providers to register as EMI homes, in response to the anticipated increase in demand.

30. The guide appears to be the first of its kind at national or local level and is an example of best practice in working with providers to develop care. The nationally recognised *Common core principles for supporting people with dementia*, guidelines on workforce development for health and social care staff, are embedded within it. It also helpfully combines information available from other sources into a single document. The guide will be launched in online form and all care providers commissioned by Adult Social Care will be provided with a link alongside associated promotional activity.

31. A key area addressed by the project was the management and reduction of challenging behaviour using best practice techniques. These centre around:

- understanding individual needs;
- managing different types of behaviour and equipping staff with skills to cope with challenging situations;
- developing activities designed to support and enhance memory, such as reminiscence work; and
- creating an environment that offers clients tailored dementia-friendly activities, for example recommending that wandering is addressed in all new care homes by building walkways or developing organised walking activities.

32. Such best practice techniques inevitably require staff to spend more time with residents. EMI homes recognise this to a certain extent as they have a higher staff to resident ratio. Adult Social Care is reflecting this need in the proposed fee structure this year, which is in part designed to encourage more homes to develop into EMI registered providers. There may be further opportunities through the commissioning or quality monitoring processes to incentivise all care home providers used by Adult Social Care to develop staff skills.

33. There will be an evaluation and ongoing monitoring of the Continuous Improvement project to assess its impact. The evaluation should be reported to the Adult Social Care and Community Safety Scrutiny Committee, given its significance to the development of dementia care practice in East Sussex. This will enable further actions to be identified as appropriate.

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### **Recommendation 3**

**The Adult Social Care and Community Safety Scrutiny Committee should consider the evaluation of the Continuous Improvement Strategy for Dementia Care Homes project in order to identify further actions required to develop practice.**

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### **Recommendation 4**

**Adult Social Care should examine all potential avenues to encourage or incentivise care homes to continue to develop the skills of their staff in relation to dementia.**

### **The Care Home In-Reach Service**

34. Sussex Partnership NHS Foundation Trust has been commissioned to pilot a new service aimed at providing tailored, on site, expert support to care homes (EMI or non-EMI) in relation to residents with dementia and complex needs, including challenging behaviour. The Care Home In-Reach Service is free to care home providers and advises them on the physical, environmental and methodological approaches to coping with behaviour that challenges. The service achieves this through upskilling staff with on site training, and reducing the prescription of antipsychotic drugs by developing alternative strategies based on psychosocial interventions.

35. The service is in its infancy and yet to be fully evaluated. However, initial findings suggest that the project is having a positive impact, including:

- reducing the number of EMI homes failing safeguarding or other conditions, which can make it more difficult for Adult Social Care to find suitable accommodation for clients; this can result in more expensive specialist care being sought;
- enabling clients to stay in care homes longer without the need for specialist care; this reduces costs and the continuity of care is better for patients;
- successfully reducing unplanned admission to hospital beds; and
- reducing the use of expensive, and sometimes inappropriately prescribed, antipsychotic drugs.

36. We welcome these initial findings, the positive feedback from care providers and the potential positive impacts in quality of life for residents who experience behaviour that challenges. However, full evaluation is required to determine whether this approach should be maintained in the longer term.

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**Recommendation 5**

**The evaluation of the impact of the Care Home In-Reach Service should be reported to the Scrutiny Committee for consideration.**

**Training packages for care homes**

37. The majority of people with dementia will eventually exhibit behaviour that challenges. It is therefore necessary for care homes to be well equipped to manage its impact on the individual, other residents and staff when it occurs. Local training is available both through the Adult Social Care training programme and from the Alzheimer's Society, both of which offer a range of courses to care home and home care staff.

38. There is now a common understanding between the two organisations of the best practice and skills required to support people with dementia, including managing challenging behaviour. The training packages cover comparable ground and have a broadly similar audience. Currently there is limited co-ordination of training between the two organisations and there may be scope to improve this to maximise impact, economy and coverage of training within the county, whilst continuing to offer choice to providers.

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**Recommendation 6**

**East Sussex County Council and the Alzheimer's Society should consider whether there are opportunities to better co-ordinate their training packages.**

## 4. Further best practice

### Dementia friendly communities

39. We have outlined a number of initiatives, recently put in place, which aim to develop and propagate best practice in dementia care within East Sussex to meet present and future needs. These initiatives are aimed specifically at care providers. However, throughout the course of the review, a wider need to develop community awareness of dementia emerged as an issue. The increasing prevalence of dementia in our communities, coupled with a lack of understanding and the stigma sometimes associated with the condition, means there is a need to demystify it. This includes encouraging local services and communities to be more responsive to the needs of people with dementia, in particular the impact of the condition on people's behaviour.

40. The Alzheimer's Society is concerned about the lack of community awareness of dementia; in particular how the public often reacts in a negative way to seeing someone displaying challenging behaviour in a public place. Only 5% of public respondents to an Alzheimer's Society survey felt that society was able to deal with people who have dementia.

41. To tackle community awareness of dementia the Alzheimer's Society recommends, "a major shift in public awareness and understanding of dementia is required to reduce stigma and encourage people to visit their GP with problems about their memory. This should combine large-scale public campaigns with targeted work to increase understanding of dementia among a range of individuals and organisations, such as the police, bank and retail outlets".

42. The Alzheimer's Society hopes to achieve this awareness through the launch of the "dementia friendly communities" programme as part of the Prime Ministerial challenge on dementia, backed by the Department of Health. The organisation describes dementia friendly communities as, "*villages, towns, cities and organisations who are working to challenge misunderstandings about dementia. Dementia friendly communities seek to improve the ability of people with dementia to remain independent and have choice and control over their lives*". Given the demographic profile of East Sussex, which means the county will experience the impact of increased dementia prevalence ahead of many other parts of the country, there is potentially a strong case for local communities to sign up to the programme. Detailed information on the requirements of this new programme is not yet available and further consideration of the specific elements would be needed to inform a decision.

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#### Recommendation 7

**Consideration should be given to the potential benefits and resource implications of applying for "dementia friendly community" status for East Sussex or specific local communities.**

## **Information**

43. The Council has a dementia webpage for local people affected in some way by dementia, and people working in dementia care. The Council is considering expanding this into a 'hub' for dementia information including details of services, latest research and government announcements. Information gathered by the Carer's Breaks Dementia Service on local services which are 'dementia-friendly' could be incorporated. The development of an information hub would be one way for the Council to support increased community awareness as well as continuing to develop the skills and capacity of care providers within the county.

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### **Recommendation 8**

**The County Council should develop the proposed website dementia information 'hub' to support increased community awareness and availability of information to care providers.**



## **Appendix: Terms of reference, membership and evidence**

### **Scope and terms of reference of the review**

44. This review arose from discussion of Care Quality Commission (CQC) inspections of Adult Social Care directly provided services at Adult Social Care and Community Safety Scrutiny Committee meetings on 8<sup>th</sup> September and 27<sup>th</sup> October 2011. During these discussions it was identified that there appears to be a lack of capacity and/or capability in the independent sector to provide residential care for people with challenging needs and behaviours due to dementia. The need for a review, focusing on care provision for people with challenging needs arising from dementia, was identified as a result.

45. The aim of the review was to assess the availability and suitability of residential and non-residential care for people with challenging needs and behaviours as a result of dementia by:

- Considering the current and potential future demand for care for people with challenging needs.
- Considering the extent to which non-residential care for people with dementia is able to manage challenging needs and behaviours effectively, particularly how health and social care services work together to provide appropriate support.
- Assessing the capacity and capability of the independent sector to provide residential care for people with dementia and challenging needs now and in the future, and how this could be developed.
- Considering best practice in the provision of care for this group of people, the extent to which this is being delivered in East Sussex, and how practice can be developed.

### **Board Membership and project support**

Review Board Members: Councillor Barnes, Councillor Ost, Councillor Pragnell (Chairman)

The Project Manager was Claire Lee, Scrutiny Lead Officer, supported by Harvey Winder, Scrutiny Support Officer

Ongoing support to the Board throughout the review was provided by Barry Atkins, Head of Strategic Commissioning, Lynn Mounfield, Head of Procurement and Nigel Blake-Hussey, Joint Commissioning Manager (Mental Health)

#### ***Project Board meeting dates***

9 February 2012, 15 March 2012, 12 April 2012, 17 May 2012

### **Witnesses providing evidence**

**The Board would like to thank all the witnesses who provided evidence.**

Barry Atkins, Head of Strategic Commissioning, Adult Social Care

Beverly Hone, Assistant Director, Strategy & Commissioning, Adult Social Care

Lynn Mounfield, Head of Procurement, Adult Social Care

Nigel Blake-Hussey, Joint Commissioning Manager (Mental Health), Adult Social Care

Darren Elliott, Project Manager, Contracts and Purchasing Unit, Adult Social Care

Sally Goodey, Project Manager, Carer's Breaks Dementia Service, Adult Social Xaew

Stephanie Giles, Community Psychiatric Nurse and Team Lead for the Care Home In-reach Project, Sussex Partnership NHS Foundation Trust

Elisa Vaughan, Locality Manager (Sussex), Alzheimer's Society

Neil Waterhouse, Service Director, Sussex Partnership NHS Foundation Trust

Dr Mandy Assin, Sussex Partnership NHS Foundation Trust

## Evidence papers

<i>Dementia 2012: A National Challenge</i> , The Alzheimer's Society, 2012
<i>National Dementia Strategy</i> , Department of Health, 2009
<i>Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy</i> , Department of Health, September 2010
Banerjee et al, 2003
<i>Dementia UK</i> , Alzheimer's Society, 2007
<i>Framework homecare providers and the care of people with dementia – a report on the current position with regard to specialist training</i> , East Sussex County Council, 2012
<i>Continuous Improvement Strategy for Dementia Care Homes</i> , various reports, East Sussex County Council, 2012
<i>Market Position Statement - Older People's Service Provision</i> , East Sussex County Council, 2012
<i>Clinical Guidelines</i> , The National Institute for Clinical Excellence (NICE)/Social Care Institute for Excellence (SCIE), 2006
<b>Additional Information Provided By Witnesses</b>
Adult Social Care (East Sussex County Council), Alzheimer's Society, Sussex Partnership NHS Foundation Trust

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