

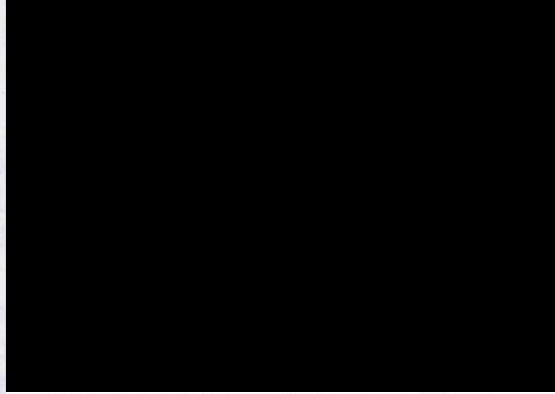
**APPENDIX D**



**Hampshire**  
County Council

**Educational Psychologist's Report  
sought under the Education Act 1996**

**Confidential**



Name of pupil: Jacob 

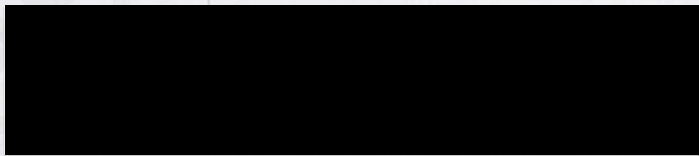
Date of birth:  12.1997

Address: 

NC year: 10

Attends:  School

Date of report: 10.07.2013

Distribution list: 



## **Appendix D: Psychological Advice**

Jacob [REDACTED]

This report is provided to assist Children's Services in carrying out a statutory assessment under the requirements of the 1996 Education Act.

All Educational Psychologists employed by Hampshire County Council are registered with the Health and Care Professions Council and are obliged to work within the HCPC's standards of conduct, performance and ethics. They hold qualifications that give them eligibility for chartered status with the British Psychological Society. This report is provided as advice to the Local Authority. It is intended to complement rather than duplicate the advice provided by parents/carers and others.

### **Background**

This report has been requested by the Local Authority as a contribution to the statutory assessment of Jacob's special educational needs. Jacob has not had direct contact with the Educational Psychology Service prior to this involvement.

Jacob was diagnosed with Klein Levin Syndrome after a period of illness in August 2011. This is a rare neurological condition which seriously affects sleep, cognitive functioning and behaviour. It is episodic in nature and an episode can last for months, weeks or days. During an episode Jacob suffers from the following:

- Excessive and disturbed sleep.
- Altered cognitive functioning – equivalent to significant learning difficulties.
- Altered behaviour – child like behaviour.
- Altered speech patterns – childish speech and communication.
- Excessive appetite.
- Confusion.
- Lack of inhibitions.

Jacob is not able to attend school, or care for himself when he has an episode of the illness. Jacob cannot be left alone as he is not safe physically and may be prone to behaviours which have difficult consequences. In between episodes Jacob returns to full health and normal behaviour. Jacob has no memory of his episodes which can lead to considerable distress and confusion when he returns to normal. This condition has a significant impact on Jacob and his family and affects every aspect of his life.

Jacob had no educational or social emotional difficulties until he developed Klein Levin Syndrome.

Jacob lives at home with his parents and twin siblings who are younger than him and attend the same secondary school. His grandmother lives locally and is a close member of the family.

This report has been informed by the following:

- Meeting with Mr and Mrs [REDACTED]
- Individual work with Jacob.
- Discussion with school staff.
- Access to professional reports.



## Appendix D: Psychological Advice

Jacob [REDACTED]

Other agencies involved in supporting Jacob and his family include:

- [REDACTED], Consultant Paediatrician.
- [REDACTED] Consultant Child Psychiatrist.
- Education Inclusion Service.
- [REDACTED] Sleep Specialist Nurse.

### Description of Jacob

#### *Physical development*

Jacob was physically healthy until he developed Klein Levin Syndrome (KLS). This condition was diagnosed in 2011 and is having a serious impact on his ability to access normal educational provision. The episodic nature of his condition means that he is able to work well when he is not having an episode of his illness but unable to learn or attend school when he is.

The main features of his condition are excessive and disturbed sleep, significant cognitive impairment, altered behaviours and confusion. When he reverts to his normal state he is unaware that he has been ill and has no recollection of the time he has lost even after a period of several months. This can be very distressing for him. He is reported to revert to a childlike state and to be unsafe to leave unattended when he is unwell. Jacob's mobility can be affected and he is inclined to bump into things and be unaware of obstacles in his path.

Jacob's longest episode has been in excess of 100 days and the largest gap between episodes is reported to be 30 days. More recently Jacob's episodes have been shorter in duration and fairly frequent.

The frequency of his episodes impacts significantly on his attendance at school and his ability to access the school curriculum. Jacob needs to be in a stress-free environment whenever possible even when he is well, as stress is considered to be a contributory factor to instigating an episode of illness. He also gets tired more easily than other students of his age as his sleep can be disturbed even when he is not in an episode of illness. He follows a sleep hygiene programme to ensure he is not over tired as again this is thought to be a contributory factor to moving into an episode of illness. Jacob is not on any regular medication but has access to melatonin if he is not sleeping effectively when he is well.

Jacob's parents have found that he has a mild intolerance to gluten and have instigated a gluten free diet to see if this improves his condition. This is a recent change and it is too early to be sure of any long term consequences.

The nature of Jacob's illness means that the school need to be aware of the signs and symptoms of Jacob moving into an episode of KLS and to have a risk management plan in place to keep him physically safe. There may be little warning of a KLS episode and he may fall asleep in unsafe or unsuitable surroundings which could cause considerable distress for Jacob if he has to be woken and moved.



## Appendix D: Psychological Advice

Jacob [REDACTED]

Jacob wears a medical wrist band to ensure others are aware of his condition. He wears glasses to correct short sightedness.

Jacob is of average height and weight and there are no other health complications reported.

### *Approaches and attitudes to learning*

When Jacob is not having an episode of Klein Levin Syndrome he is highly motivated to learn and wants to work as much as he can to make up for the times he is unable to work due to his illness. He demonstrates a keen desire to do well and does not want his condition to interfere with his ability to achieve academically. He readily asks for help and seeks out relevant adults when he needs to.

When Jacob is in an episode of his illness he is unable to attend school, learn or attempt any educational programmes. His cognitive functioning is impaired to an extremely low level and he reverts to a child like state.

Jacob's attendance was 30% in Year 9 and has been 35% in Year 10. This has serious implications for the amount of progress Jacob can make in his academic performance.

Jacob is now accessing home tutors from the Education Inclusion Service, one for Maths and one for English. He is unable to work with them when he is ill but works intensively with them at home when he is well to catch up on the curriculum areas he has missed at school.

Jacob is following a reduced timetable, taking five subjects, English, Maths, Science, IT and Engineering, four of which are GCSE subjects. He has taken his GCSE Maths early in order to reduce the risk of missing all of his exams at once due to an episode of illness. He has also taken two modules of his science course so that if he is unable to attend his exam he can receive an estimated grade. The current focus is on improving the English curriculum that he is following.

Jacob attends school when he can but has some time designated for working at home with his tutors and for independent study. When he is at school he has the option of joining the class or working independently in a quiet area depending on how well he feels. The class teachers provide some individual catch up time with Jacob when they are available.

Information is provided to all staff regarding Jacob's condition in order to ensure understanding and safety. The Examination Boards are also being kept informed of Jacob's condition and exemptions are being requested as appropriate.

Jacob is interested in a career in IT and has identified a course at Brockenhurst College which he plans to follow. A transition plan has been put in place by the school, college and parents. Jacob will transfer to college in September 2014.



## Appendix D: Psychological Advice

Jacob [REDACTED]

### *Speech and communication skills*

When Jacob is well, he has good verbal language and an extensive vocabulary. When I was working with Jacob he completed some incomplete, unstructured sentences. This was to provide an opportunity for Jacob to express his thoughts and ideas without too much adult influence. I noted that some of his responses demonstrated a tendency towards a literal understanding of language and a preference for dealing with facts rather than feelings. For example, "When I was younger.....I was not as old as I am now" and "The happiest time...7.30pm".

However reports from school suggest he has good creative writing skills, and he is reported to read extensively so this does not appear to be an area of concern, rather a preference for dealing with information.

When Jacob has an episode of illness his communication skills regress significantly. He can produce child-like language or not talk at all. His level of understanding is also very limited and is reported to become more literal than when he is well. This would appear to be a personal trait that becomes more apparent when he is in an episode.

There are no significant concerns about Jacob's speech and language development when he is well.

### *Cognitive development*

The Child Clinical Psychology Department at Southampton General Hospital administered a battery of tests to identify Jacob's cognitive abilities both when he was well and when he was in an episode of Klein Levin Syndrome.

The findings suggested that Jacob's abilities fall within the average range with strengths in verbal memory and some relative weakness in the speed of information processing. However the specific subtest that he was weaker on involved an element of motor control and speed, suggesting that it is his motor skills that delay his performance, rather than his cognitive skills.

When Jacob is in an episode of KLS his scores on equivalent tests fell within the extremely low range in all subtests. He also found it difficult to understand and follow the instructions which he had managed perfectly well when he was well. He became upset when corrected and was more literal in his understanding. Significantly, it took him three times as long to complete the tests as when he was well.

Jacob's attainments at school were well within the average range prior to his illness. His literacy scores are still higher than average for his chronological age.

He is predicted to attain A/B grades in his GCSEs now that he is on a reduced timetable and has individual support via the Education Inclusion Service.

Jacob has no added learning difficulties other than those exhibited during his episodes of illness.



## **Appendix D: Psychological Advice**

**Jacob** [REDACTED]

### *Social emotional and behavioural development*

Jacob is a polite, well mannered and well liked student. He socialises well with peers and has some friendships that are very supportive.

Jacob's illness has a significant impact on him and the family and he gets distressed by the consequences of it at times. It would be unusual if this was not the case.

When Jacob is in an episode he is unpredictable and difficult at times. His behaviour regresses significantly and his inhibitions are lowered meaning that he may do things that are out of character and could have lasting consequences. Jacob needs constant attention to ensure that he is physically and emotionally safe and that any unusual behaviours can be pre-empted and managed effectively. This is clearly very demanding and distressing for the whole family including Jacob's siblings.

When working with me Jacob said to me that he "Doesn't do emotions". When I asked him what happened to them he said that he pushed them down and then they decayed. On further discussion I did not find any indication that this was causing any problems for Jacob at the present time. There may come a time when he wishes to discuss how his illness is impacting on his life and how he manages the emotions that arise from it, but currently he is managing himself in line with his personality and with the support of his family and friends.

### *Independence and self help skills*

When Jacob is well he is able to look after his own basic needs without any difficulties. When he is in an episode of his illness Jacob needs constant attention and his family have to ensure that he is safe and that his basic needs are met.

Although Jacob is able to be independent when he is well, the risk of him moving into an episode of his illness when he is out and about without support limits his ability to be as independent as most students of his age. This is being managed well by his family at the moment. As Jacob matures it will be important that he feels he has some control over how he manages the tension between wanting to be independent and needing to be safe.

### **Jacob's views**

Jacob is finding that the current arrangements between school, tutoring and independent studying is working well for him. He prefers working with an individual tutor as he is able to learn more effectively when he is well. The pace and the level of challenge can be directed specifically for his needs and he is finding the work interesting and stimulating. It also means that the tutor can pick up exactly from the point where Jacob has stopped working rather than Jacob having to catch up with a class who have moved on from where he was which was difficult and frustrating for him. Jacob would currently like more English tutoring as he has taken his GCSE Maths exam. However he will re-take his exam in November if he does not get an A.



## **Appendix D: Psychological Advice**

**Jacob** [REDACTED]

Jacob enjoys going to school when he feels well enough and feels that the staff are trying hard to support him. He likes to see his friends at school and joins them at break and lunchtime even if he is not working in the classroom.

In discussion Jacob did not want to spend time talking about his illness and wishes that he didn't have it. He also worries that he may not grow out of it. The prognosis suggests that most young people grow out of it by the time they are 30 years old.

Jacob says that he enjoys reading, gaming, spending time on the computer and likes to keep up with current affairs. Jacob reports that he is happiest when he is on his own and finds other people annoying at times. As with most 15 year old students he finds his younger brother and sister annoying at times. At school he sometimes gets told off for correcting other students and is frustrated when he does not learn as much from the class as he would like to have done. Jacob is enjoying his current work placement within school. He is helping to develop some graphic work in the IT department. He is also looking forward to going to college.

### **Parents' views**

Mr and Mrs [REDACTED] are obviously concerned that Jacob gets as much out of his education as he can when he is well. Since Easter they feel that things have been going better from an education perspective. The home tutoring and the reduced timetable are working well for Jacob and the family. Sometimes, however, communication between home, school and the tutors is not as good as it could be, with some mixed messages occurring at times.

Jacob is very good at studying independently and needs to be encouraged to take breaks and get fresh air. He is very keen to make up the time when he is in an episode of illness which can make him sensitive to things that interfere with this.

Jacob's illness has had a major impact on the family, the younger children being affected too. They are concerned about bringing their friends home in case Jacob is unwell and feel that they must watch him carefully in case he is going into an episode. The family are in contact with a support network for young people with KLS which they are finding very helpful and supportive. On discussion about what they felt could be improved for Jacob, they were of the opinion that it would be helpful if educational provision could be more flexible so that Jacob could "bank" hours of support when he was ill to be used when he was well. They would also like Jacob to be able to benefit from educational support in the holidays if that is when he is well in order to optimise the time he spends on his education when he is able to learn.

### **Discussion**

Jacob is a polite well mannered young man who wants to do well academically. He enjoys computers, reading and socialising with his friends. He is of at least average ability and his literacy skills are above his chronological age. Jacob wishes to go to college to study computing when he leaves Priestlands School.



## **Appendix D: Psychological Advice**

**Jacob** [REDACTED]

*Jacob was doing well at school and there were no concerns about his* development until 2011 when he was diagnosed with Klein Levin Syndrome (KLS). This is a rare neurological condition which is episodic in nature and affects sleep, cognitive impairment and behaviour. When Jacob is experiencing an episode of KLS he has extremely low cognitive abilities, child-like behaviours and immature communication patterns. He is unsafe to be left alone and cannot look after his own basic needs. At these times Jacob cannot access education either physically or cognitively. Episodes of the illness can last for days, weeks or months and when he returns to his normal functioning he has no memory of the time he was unwell. This is very distressing for him and he needs support to get over these episodes. Jacob moves in and out of episodes very rapidly necessitating those around him to be aware of the signs and symptoms in order that he can be in a safe environment if he moves into an episode. The prognosis for this illness is that Jacob will grow out of it but it could last until he is 30 years old. Jacob's illness is having a significant impact on him, his family and his education.

Jacob is currently accessing a reduced timetable at school and concentrating on five subjects. He is being supported by tutors at home from the Education Inclusion Service. The school are ensuring that all staff are aware of Jacob's needs and a risk assessment is in place to ensure he is safe. Clear and frequent communication between school, home and tutors is essential. Jacob wants to go to Brockenhurst College to study computing when he leaves school.

Jacob has significant special educational needs associated with his medical condition. These needs will continue while Jacob is suffering from the illness which is likely to be throughout his education provision.

Jacob's school and family are supporting him well but his condition is having a significant impact on him and all who work and/or socialise with him. Jacob's condition makes it difficult for him to be independent as even when he is well, measures must be in place to ensure he is protected in case he moves into an episode unexpectedly. Jacob's development into an independent young adult will have to be balanced carefully with the need to manage his illness.

### **Aims of provision**

Jacob will benefit from provision which aims to:

- Support him to develop his academic potential by offering a flexible approach to accessing the curriculum and optimising the periods of time that Jacob is well. Jacob will benefit from accelerated learning when he is well.
- Provide a quiet, stress free environment for Jacob to work in when he does not feel well enough to work in the classroom, including individual support at home.



## **Appendix D: Psychological Advice**

### **Jacob [REDACTED]**

- Provide a safe environment for Jacob should he move into an episode of illness at school, a risk assessment and management plan will need to be in place.
- Modify aspects of the timetable to accommodate Jacob's health needs, including flexibility around exam arrangements.
- Continue to provide opportunities for Jacob to socialise and feel part of a social group.
- Maintain effective and supportive social relationships. Jacob may get frustrated with other students when they are not working as diligently as he is. It is important that he is supported to manage this well so that it does not impact adversely on his social relationships.
- Develop ways of ensuring Jacob feels re-integrated into the school community after he has had a period of absence, including understanding what he has missed socially as well as educationally.
- Develop healthy learning patterns by ensuring he takes appropriate breaks when he is working intensively.
- Ensure that Jacob maintains a balance between work and leisure so that he maintains a balanced approach to his lifestyle.
- Support Jacob to develop as an independent young man as far as the restrictions of the illness allow. He would benefit from being involved in all decisions about the management of his illness in order that he can take some control over it as he matures.

### **Facilities and resources**

Jacob would benefit from:

- Teaching staff who understand the nature of Jacob's illness and how to manage it safely
- Effective risk assessment and management plans
- Support to catch up missed work with relevant class teachers on an individual basis.
- A Key Worker to facilitate effective communication between home, school and the Education Inclusion Service.
- Support staff who are available for Jacob to discuss any worries or concerns about his progress academically, socially or emotionally
- Opportunities for independent working in a quiet, stress free environment.



## Appendix D: Psychological Advice

Jacob [REDACTED]

- An appropriate and supportive peer group.
- Provision characterised by flexibility in all aspects of Jacob's education.
- Home tutoring to support Jacob when he is unable to meet the demands of the school setting.
- Close communication with the Exam Boards.

If anyone wishes to discuss this report with me, please ring [REDACTED] or write to me at the above address.

**This report will be made available to parents and may become part of a legal document (the Statement). It may be required by the Special Educational Needs Tribunal in the event of a parental appeal.**

[REDACTED]

[REDACTED] Chartered Psychologist.

BSc. (Hons), MSc.(Soc.Psych.), MSc, (Ed,Psych), PGCE, Cert. Reality Therapy

lh/st/App D/ [REDACTED]  
3.7.13